Quality of life and its measurement in nursing homes

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Quality of life and its measurement in nursing homes

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Voor Riet en Karen Gerritsen

Quality of life and its measurement in nursing homes

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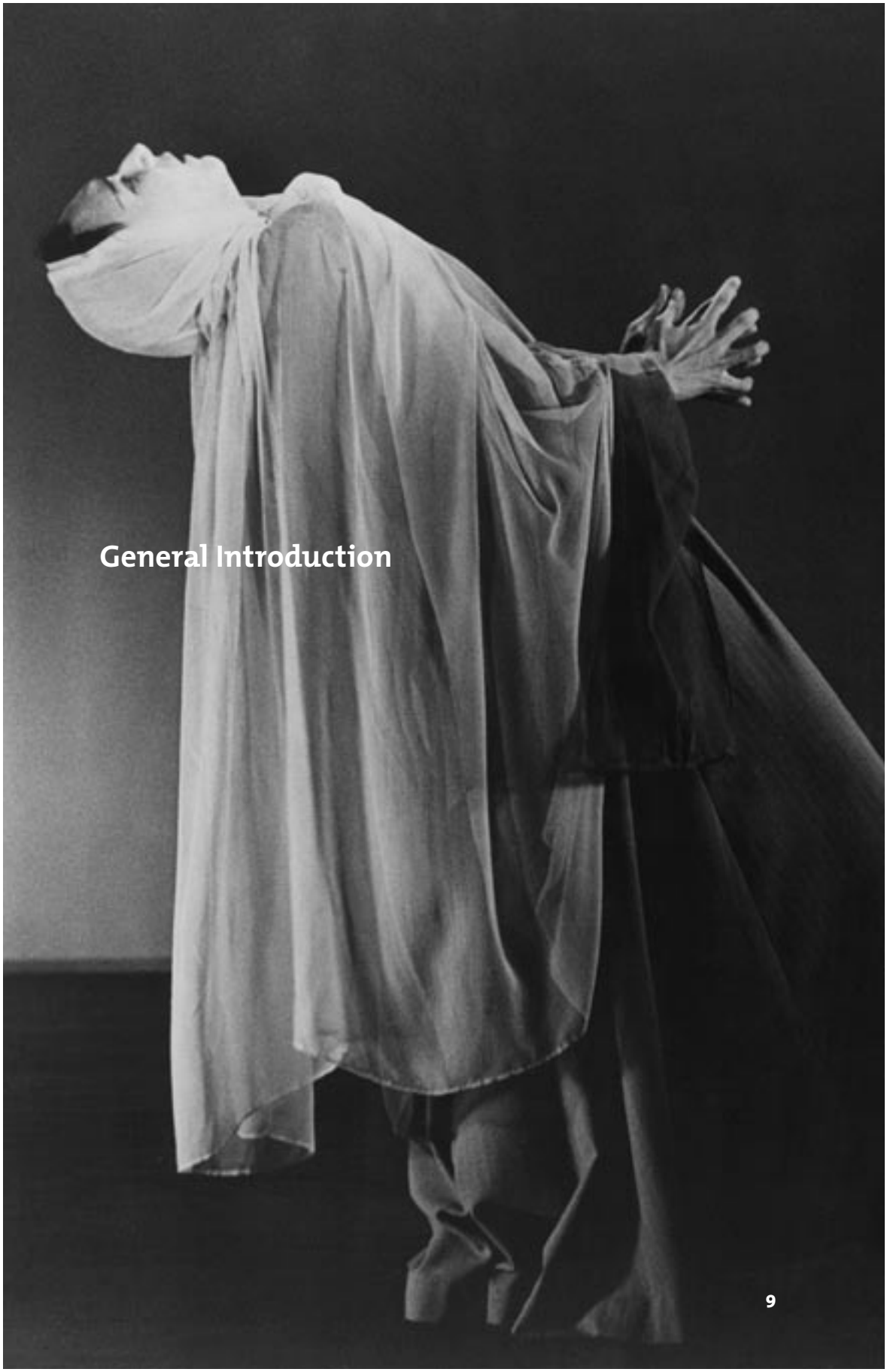

General Introduction

Throughout this thesis, feminine pronouns will be used when describing residents, because female nursing home residents are in the majority. Of course, this also includes male residents.

Chapter 1

General Introduction

The basic ambition of nursing homes has long been to provide their residents with care of high quality. The quality of their care was predominantly indicated by markers of poor health care, such as dehydration, pressure ulcers, falls and urinary tract infections (Kane, 2001; 2003). Yet, the quality of life (QOL) as experienced by the residents is increasingly being recognized as an important outcome of care. QOL is not only based on medical and functional health status but also, and perhaps even more so, on social and psychological well-being. The focus on QOL reflects a shift in care methodology towards a client-oriented (i.e. consumer-based) approach (Noelker, 2002; Brown, Renwick & Nagler, 1996). Individual preferences of the resident (i.e. client) become an important part of the care plan, in addition to the traditional care needs. Moreover, instead of focusing only on the problem-oriented needs and disabilities of the residents, care targets are more concerned with their strengths and abilities. This wider perspective allows care-providers to contribute more effectively to the QOL of the residents, which is increasingly becoming the central purpose of these facilities.

Nursing home residents form a diverse population. In general, though, they are elderly people whose problems in the physical, social and psychological areas of their life are so severe that they can no longer live independently. In the Netherlands, a nursing home can typically be described as 'an institution that provides temporary or permanent multidisciplinary treatment, guidance, support and nursing care, mainly for elderly patients with long-term, complex health problems, expressed primarily in terms of functional disorders and handicaps' (Ribbe, 1993). At the moment there are approximately 330 nursing homes in the Netherlands for a total of 57,000 residents (Prismant & Arcares, 2002). Most of these nursing homes have separate units for residents who mainly have physical

handicaps, so-called 'somatic units', and for residents who mainly have dementia syndromes, so-called 'psychogeriatric' units.

Due to their frailty, nursing home residents need considerable help in maintaining their QOL. To contribute effectively to the QOL of these residents, a comprehensive measurement of QOL is a necessary first step. However, this is easier said than done. Firstly, a clear understanding of the concept of QOL is a prerequisite for the measurement of QOL, and, although it has become an important focus in research as well as in clinical practice, there is still no consensus on what exactly QOL is and how it can be optimized (Kane, 2003). Secondly, the measurement of QOL is complicated by the fact that many residents, in psychogeriatric *and* in somatic units, are not able to communicate their feelings, needs and preferences effectively. Residents with dementia and stroke survivors, most of whom suffer from considerable communication difficulties, form up to 75% of the nursing home population (Prismant & Arcares, 2002).

Accordingly, the objective of this thesis is to find a conceptual *approach to quality of life* that is suitable for use in nursing homes and, on the basis of that approach, to obtain a means for adequate *measurement of quality of life*.

Approach to quality of life

There is widespread agreement that QOL concerns well-being in a broad sense, and that it should be considered as a multidimensional rather than a one-dimensional construct. However, the approaches to QOL vary with regard to the dimensions they include. The approaches can generally be grouped into two categories, i.e. comprehensive and partial. Comprehensive approaches to QOL aim to include all dimensions of life. They pertain to the general population (e.g. Shye, 1989; Ferrans, 1996; Lindenberg, 1996), or to a specific group, such as elderly people and psychiatric patients (e.g. George & Bearon, 1980; Lawton, 1991; Hughes, 1990; Stewart & King, 1994; Fernandez-Ballesteros, 1995; Brown, Renwick & Nagler, 1996; Van Nieuwenhuizen, Schene & Koeter, 2001; Angermeyer & Kilian, 1999). Partial approaches include only dimensions that are directly influenced by a concept of specific interest, such as health-related approaches (e.g. Patrick & Erikson, 1993; Wilson & Cleary, 1995) and disease or disorder specific approaches (e.g. Brod, Stewart & Sands, 1999; Rabins & Kaspar, 1997; Gurland & Katz, 1997). Typically, in the health and disease-related approaches, dimensions are considered to be relevant when they are directly influenced by health or a disease, whereas in group-specific approaches dimensions are considered to be relevant when they are highly important for a particular group, irrespective of whether these dimensions are influenced by their condition.

In addition, many approaches to QOL only describe the dimensions, but do not provide a rationale for their inter-relationships (Wilson & Cleary, 1995; Logs-

don et al., 1999; Rabins & Kaspar, 1997). Only when these relationships are known it is possible to optimize specific (sub-)dimensions (or overall QOL) through guided intervention goals. For instance, losing the use of one's legs regards, in itself, a physical dimension, but it will probably have an impact on social and/or psychological dimensions as well. An approach that clarifies how the QOL dimensions are inter-related provides not only an explanation for which dimensions may be affected, but also how, in turn, the overall QOL is affected. As such, it indicates the required focus for an intervention to maintain or enhance QOL.

Measurement of quality of life

As far as measurement is concerned, there is ongoing discussion about the most appropriate way to measure QOL. In general, however, there is consensus that it should be based on the subjective experience of the individual. Ideally, therefore, the individual should provide the information about her own QOL. However, as indicated, many nursing home residents are not able to evaluate their situation or express their satisfaction adequately, so that others, for instance care-providers or relatives, have to report on their behalf. Observational instruments facilitate assessment of the entire nursing home population and therefore seem to be the obvious choice for uniform measurement of QOL. Measurement based on self-report implies the exclusion of highly relevant sub-groups of nursing home residents (up to 50%), and thus leads to unrepresentative results (Sneeuw, Sprangers & Aaronson, 2002). Furthermore, with observational instruments, all residents can be monitored during their entire stay, irrespective of the fact that, in general, their condition will deteriorate. Therefore, the focus in this thesis is on observational methods to measure QOL, although self-report measures will also receive some attention.

Minimum Data Set

The most extensively tested and evaluated comprehensive observational measurement instrument for use in long-term care is the Minimum Data Set (MDS) of the Resident Assessment Instrument (RAI) (Morris, Hawes, Fries, Phillips, Mor, Katz, et al., 1990; Holtkamp, 2003). The RAI is a system for client-monitoring and problem-analysis that supports the care-process, and especially the care-planning process. The MDS is a set of 100 items (in addition to several identification items), covering the resident's functional, medical, psychosocial and cognitive status, and is assessed quarterly by a nurse (Morris et al., 1990). Most items are formulated as observational items, and although the RAI manual instructs staff to interview residents before making a categorical judgment about their status, several studies suggest that these interviews are often not included in the MDS assessment (Schnelle, 2003), which implies that the MDS often contains only observational data. On the basis of the MDS assessment, the RAI system signals

the (possible) presence of specific problems. By means of standardized protocols, the RAI provides a systematic analysis of the signaled problems. It was originally developed in the United States, and has subsequently been introduced in various countries, including the Netherlands.

The MDS is divided into sections, each containing a number of items on a specific aspect of functioning or health, for instance cognition, communication, vision, mood, and disease diagnoses. The items are grouped around the various aspects according to content, and have individually been found to be reliable (Morris et al., 1990, Hawes et al., 1995; Frederiksen, Tariot & De Jonghe, 1996). The items in one section do not necessarily form an internally consistent scale for an overall construct (see Appendix 1 for the MDS). Nonetheless, certain MDS items have been used in the construction of measurement scales. So far, five MDS scales have been published: the Cognitive Performance Scale (CPS) (Morris et al., 1994), the Index for Social Engagement (ISE) (Mor et al., 1995), the ADL-Self-Performance Hierarchy (ADL-SPH) (Morris, Fries & Morris, 1999), the Depression Rating Scale (DRS) (Burrows et al., 2000), and the Changes in Health, End-stage disease and symptoms and signs score (CHESS) (Hirdes, Frijters & Teare, 2003), which measures health instability. These scales aim to enable care-providers to monitor an individual resident's status and detect changes over time.

Although the MDS is a rich source of information, it is still a question whether it can be used in the measurement of QOL. For instance, it seems to pay relatively little attention to aspects of psychosocial well-being. Moreover, most items, including the psychosocial items, refer to problems or deficiencies, and potential strengths and vitalities in the functioning of residents seem to be under-exposed. Thus, in order to determine the usefulness of the MDS for measuring QOL, the psychometric properties of the already existing MDS scales are tested and their fit to a QOL approach is studied. Furthermore, the usefulness of other MDS items in the measurement of QOL is determined. An outline of the thesis and the specific research questions is given below.

Research questions and outline of the thesis

1 *Are there existing QOL frameworks or approaches that focus on the entire elderly nursing home population, and can these be used as a basis for enhancement of QOL?*

Before addressing the measurement of QOL, it is necessary to have a suitable conceptualization of QOL. Accordingly, in Chapter 2, different conceptual approaches to the QOL of frail elderly people are identified in the literature and evaluated according to three criteria that are crucial for determining whether or not a framework can be a useful basis for the enhancement of QOL in nursing home residents. On the basis of this systematic analysis, the most useful

approach is selected and discussed in the light of its applicability in the nursing home population.

2 *What is the reliability and the validity of the existing MDS scales in daily nursing home practice in the Netherlands?*

As a first step in determining the usefulness of the MDS in the measurement of QOL, the psychometric properties of the existing MDS scales are discussed in Chapters 3 and 4. The Cognitive Performance Scale (CPS) (Morris et al., 1994), the ADL-Self Performance Hierarchy (ALD-SPH) (Morris et al., 1999), and the Depression Rating Scale (DRS) (Burrows et al., 2000) are dealt with in Chapter 3. With the exception of the CPS (Hartmaier et al., 1995), these scales have not yet been validated on independent samples. Moreover, the reliability and validity of the scales in daily practice in the Netherlands may not be the same as in the United States, and need to be determined. The Index for Social Engagement (ISE) (Mor et al., 1995) is discussed in Chapter 4, its construct validity is questioned, and an attempt is made to improve its reliability and validity.

3 *Can a scale for challenging behavior be constructed on the basis of MDS items?*

To determine whether or not the MDS can be used for the measurement of QOL, this thesis predominantly considers psychosocial aspects, because these seem to be under-represented in the MDS. Most of the remaining psychosocial items (i.e. not incorporated in existing MDS scales) concern negative interaction. Indeed, the need to have a scale for challenging behavior based on the MDS has often been expressed by nursing staff, especially by staff working on psychogeriatric units. However, the conceptualization of challenging behavior is far from clear. Therefore, Chapter 5 describes a new approach to the concept of challenging behavior, in which it is linked to QOL. Also investigated is whether a valid challenging behavior scale can be constructed on the basis of existing MDS items.

4 *Can, in addition to the mds, a reliable and valid positive observational scale for social well-being be constructed that fits the selected approach to QOL?*

It was argued earlier that the MDS does not provide sufficient positive information on social well-being. Therefore, a set of items, based on the selected approach to QOL (see question 1), was developed and added to the MDS. Chapter 6 describes the construction and validation of a new observational scale for positive social well-being.

5 *What is the usefulness of self-report overall QOL scales in nursing homes?*

The last question that is addressed in this thesis refers to its starting point, i.e. the use of observational measures. Observation is necessary in the assessment of all residents during their entire stay in the nursing home. Nevertheless, the individual resident herself is the most obvious source of information for measuring concepts that involve subjective well-being, and at least some residents will be able to self report. Therefore, it was also investigated whether there are any existing self-report scales that are suitable for those residents and measure overall QOL. In Chapter 7, the usefulness of six self-report scales for overall QOL is investigated, including which scales can be administered reliably and validly to which residents.

Finally, in Chapter 8 the main findings and conclusions are summarized and discussed, and it is established whether the MDS is, indeed, the required instrument for the measurement of QOL. The relevance of this study for further research and clinical practice is also discussed.

Finding a useful conceptual basis for enhancing the quality of life of nursing home residents





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Chapter 2

Finding a useful conceptual basis for enhancing the quality of life of nursing home residents

This chapter focuses on the QOL of elderly people whose problems in the physical, social and psychological domains of life are so severe that they have to live in a nursing home. These people, in particular, are a significant group because, due to their frailty, they probably need help to maintain a high level of QOL. Moreover, many residents are not able to communicate to others their wants, needs or satisfaction. This makes it especially important for caregivers and relatives to know what constitutes QOL in this population and how it can be maintained or increased. This knowledge provides them with tools to support the residents adequately in optimizing their QOL. Furthermore, it can serve as a conceptual basis for the development of effective guidelines on which the nursing home staff can base their QOL-enhancing policies.

In the literature there is widespread agreement that QOL concerns well-being in a broad sense, and that it consists of various dimensions. However, for effectively optimizing QOL, it is necessary to know what these dimensions are and what they include, what their specific sub-dimensions are, and also how different (sub-)dimensions combine to constitute QOL. For example, do all (sub-)dimensions contribute to QOL to the same extent, can QOL still be high when one or more (sub-)dimensions are impaired or have been lost, and, do losses in one (sub-)dimension also affect the contribution to QOL of other (sub-)dimensions?

The aim of this chapter is to review and evaluate existing QOL frameworks that focus on the entire elderly nursing home population, in order to determine whether these can provide practical tools for QOL-enhancement and serve as a basis for guidelines to assist the nursing home staff in optimizing QOL. The existing frameworks or approaches will be evaluated according to three criteria that

are deemed essential for frameworks serving as a basis for QOL-enhancement in nursing home residents.

The first criterion is the prerequisite that any framework should be based on assumptions about the *comprehensive* QOL of *human beings in general*. A basically restricted view on QOL that is not comprehensive (such as health-related QOL) may result in erroneously excluding relevant aspects of QOL. Furthermore, to have a universal base, thus, to start with human beings in general (instead of, for instance, patient-specific or group-specific QOL) is necessary to thoroughly evaluate the relevance of different (sub-)dimensions of the broader concept. Although differences between groups in the relative importance of certain (sub-)dimensions may exist, at present there is no evidence to show that QOL in nursing home residents is *fundamentally* different. When starting from a perspective that is both comprehensive and based on human beings in general, i.e. has a universal base, it is possible to determine which dimensions are affected by the resident's condition, and which are still intact and may therefore contribute to the resident's QOL. As intact dimensions may serve as 'strengths' that compensate for losses in other dimensions, tools for optimizing QOL should not only focus on impaired or lost dimensions, but also on intact dimensions. Hence, a framework of QOL should focus on both.

The second criterion is that a framework should not only define the dimensions of QOL, but should also explain how and to what extent each (sub-)dimension contributes to QOL and how these dimensions are inter-related. For instance, if QOL is considered to consist of a physical, a psychological and a social dimension, it should be clear whether each dimension contributes to QOL to the same extent, or if, for instance, the physical dimension is more important than the other two dimensions. It should also be clear how the other dimensions and QOL in general change when a certain dimension of QOL is affected. Can QOL remain stable or be recaptured? For example, when a resident loses her spouse, the framework should explain what (sub-)dimensions are affected, how this affects her QOL, and whether and how she can influence it.

The third and final criterion is that a framework should also provide insight into how inter-individual differences can be represented. When trying to optimize QOL, the nursing home staff must be able to take the individual preferences of a resident into account. At the individual level there may be considerable differences in the relative significance and content of a (sub-)dimension. Social support, for instance, may be a specific sub-dimension of a social dimension, but individuals may differ in their need for support and from whom they would want it (a spouse, a child, a priest, or nursing home staff). Thus, to achieve effective QOL enhancement that is tailored to individual residents, the framework should take individual preferences into account.

Summarizing: only a QOL framework that is based on a broad and universal perspective, that illustrates how (sub-)dimensions contribute to QOL, how (sub-)dimensions are inter-related, and how individual preferences relate to specific dimensions, can provide the nursing home staff with the necessary tools to decide on how to support the residents in optimizing their QOL. This framework can also be used as a tool to evaluate existing QOL measurement instruments with regard to their applicability to the nursing home setting, or to structure the development of an instrument that can be used to evaluate QOL-enhancing interventions in nursing home care. Ultimately, it can be the basis in the development of guidelines for effective QOL-enhancement in nursing homes.

This chapter first describes the search strategy that was used to identify the frameworks. Subsequently, the identified frameworks will be briefly discussed and evaluated according to the criteria mentioned above. Although this brief description will probably not do justice to all that has been written about the frameworks, the aim is to explicate their essence, so that the evaluation process is transparent. In the discussion of the frameworks, the original terminology will be adhered to. For instance, the (sub-)dimensions of QOL are referred to as sectors, domains, factors, etc.. Finally, the framework that meets the criteria best will be described in more detail, the conclusions will be summarized and recommendations for future research will be discussed.

Search strategy

Published literature on frameworks relating to the elderly nursing home population or to frail or disabled elderly persons was considered relevant. As authors use different names for their theoretical frameworks, several keywords were used in addition to 'frameworks' in the search. The keywords *approach, model, framework* or *theory* in combination with *quality of life* and *frail* or *disabled elderly*, or *nursing home(s); care home(s); residential home(s); long-term care facility(-ies)* or *long-term care institution(s)*, were applied to all available Psychinfo (1887-), Pubmed/Medline (1966-) and Sociofile (1974-) databases running until April 2001. In total, 791 references were identified. First, it was checked which of these needed to be excluded because the abstract unmistakably showed that the publication was not about a framework for QOL. It appeared that many utilized QOL as an outcome measure of a behavioral or pharmaceutical intervention or epidemiological study, which led to exclusion. Another group of publications was excluded because these pertained to quality of care and care methods, and QOL was only mentioned as one of the relevant goals. Then the abstracts of the remaining 34 publications were checked to determine which of the frameworks clearly did not apply to the nursing home population in the broadest sense but to a specific selection, such as dementia patients, stroke patients or people with developmental disabilities. This led to the exclusion of 23, which left 11 publica-

tions of which the complete text was retrieved (Birren, Lubben, Rowe & Deutchman, 1991; Lawton, 1991; Faulk, 1988; Goode & Hogg, 1994; Kivnick, 1993; Green & Cooper, 2000; Ball et al., 2000; Albrecht & de Vlieger, 1999; Kempen, Brilman & Ormel, 1998; Ormel, Lindenberg, Steverink & Vonkorff, 1997; Raphael, Brown, Renwick & Rootman, 1997).

After reading the publications and related research carried out by the authors, another 5 publications were excluded. Albrecht and De Vlieger's study (1999) was excluded because their study population did not consist of elderly people (mean age was 53). The research carried out by Kivnick (1993), in collaboration with Erikson and Erikson (1986), was excluded because it appeared to refer to QOL only implicitly. Finally, the Raphael et al. study (1997) was excluded because it focuses on community-dwelling elderly people and is not applicable to *frail* elderly people without further elaboration (D. Raphael, personal communication). Consequently, 6 potentially suitable frameworks could be examined in further detail on the basis of the three criteria.

Describing and evaluating the frameworks

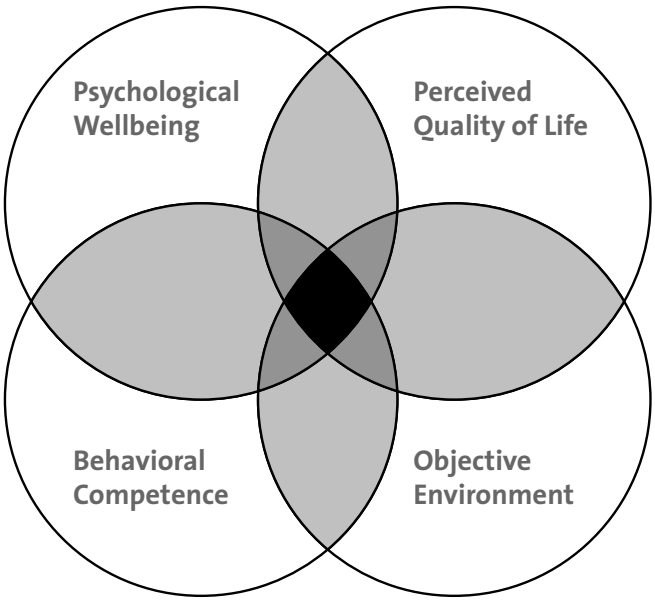
In the following, first the reports on the six frameworks will be briefly summarized, in chronological sequence of publication. Each framework will then be evaluated according to the three criteria that a QOL framework should meet if it is to serve as a basis for QOL-enhancement. The criteria will be numbered, to facilitate reading.

Lawton's four sectors of the good life

Lawton (1983; 1991) adapted his original framework of *the good life* (1983) to include frail elderly people (1991) and dementia patients (1997, 1994). He defines the QOL of frail elderly people as *"the multidimensional evaluation, by both intrapersonal and social-normative criteria, of the person-environment system of an individual in time past, current, and anticipated"* (1991, pp. 6; see Figure 1). On theoretical grounds, he distinguishes four sectors of QOL that partly overlap. He considers every sector as an independent possible indicator for QOL measurement: 1) *behavioral competence,* i.e. the individual's ability to hold her own in functional and social respect. Behavioral competence is a hierarchy of competence categories that is based on a system view of human beings. It represents social normative evaluations of the person's functioning in the health, cognitive, time-use and social dimensions. 2) *Domain-specific perceived QOL* is considered to be a person's subjective evaluation of function in the behavioral competence dimensions. The method of itemization determines the specific content of the sector, as is the case with the behavioral competence sector. Lawton considers behavioral competence and perceived QOL to be the central sectors of QOL. The other two are not central sectors, but essential components of *"a loose causal*

model" (1991, pp.10). 3) *Objective environment* consists of both physical and interpersonal domains. What aspects of the objective environment are relevant to a particular person depends on their relevance to both behavioral competence and domain-specific perceived QOL. Some aspects are prerequisites to, i.e. building blocks for, dimensions of behavioral competence or domain-specific perceived QOL, others are catalysts. 4) *Psychological well-being* is *"the ultimate outcome in a causal model of the open type"* (1991, pp. 11). It is defined as *"the weighted evaluated level of the person's competence and perceived quality in all domains of contemporary life"* (1991, pp.11). A structure that integrates past, present and future experiences, *the self,* does this weighting.

Figure 1. Lawton's Four Sectors of the Good Life



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Criteria

1) COMPREHENSIVENESS AND UNIVERSALITY: The first criterion is met by Lawton's framework. In one of his first publications on the good life (1983), Lawton mentions QOL as "a grandiose construct, presuming to account for all of life, which subsumes all that we define as legitimate personal and social goals. Its sectors together include every aspect of behavior, environment and experience" (1983, pp. 349).

2) Inter-relatedness: The contribution of the (sub-)dimensions to QOL and the inter-relations of the (sub-)dimensions are ambiguous in Lawton's sector-approach. Firstly, he considers the sector psychological well-being to be the ultimate outcome, but it remains uncertain as to whether this is the same as QOL. Secondly, although he regards psychological well-being to be the weighted evaluation of the two central sectors (behavioral competence and perceived QOL) and thus suggests a hierarchical approach with behavioral competence and perceived QOL as determinants, this relationship is not represented in his visualization of the framework as four overlapping circles (see Figure 1). The statement that objective environment (sector 3) is a prerequisite or catalyst for behavioral competence and domain-specific perceived QOL (sectors 1 and 2) does not correspond with Figure 1 either. Moreover, he states that domain-specific perceived QOL is the subjective evaluation of behavioral competence. How that relates to psychological well-being as the weighted evaluation of the two is not clear. It is also not clear if and how losses in one of the sectors influence other sectors.

3) Individual preferences: In Lawton's view, the sectors of behavioral competence and perceived quality are weighted into psychological well-being, which is dependent on the (interpretation of the) individual. Therefore, it appears that psychological well-being, the central outcome, is dependent on individual preferences and circumstances. He also states in his 1991 publication that *"the intrapersonal aspects of QOL express one essential ingredient of a comprehensive conception, that each individual has internal standards and evaluations of life that are idiosyncratic and not totally accountable to any external standard"* (1991, pp. 7). Clearly, Lawton attributes importance to individual preferences. However, it is not clear to what *"intrapersonal aspects"* he refers. Moreover, because it is not clear how these aspects are related to other 'aspects' of QOL, there are no indications as to how to use them to optimize QOL.

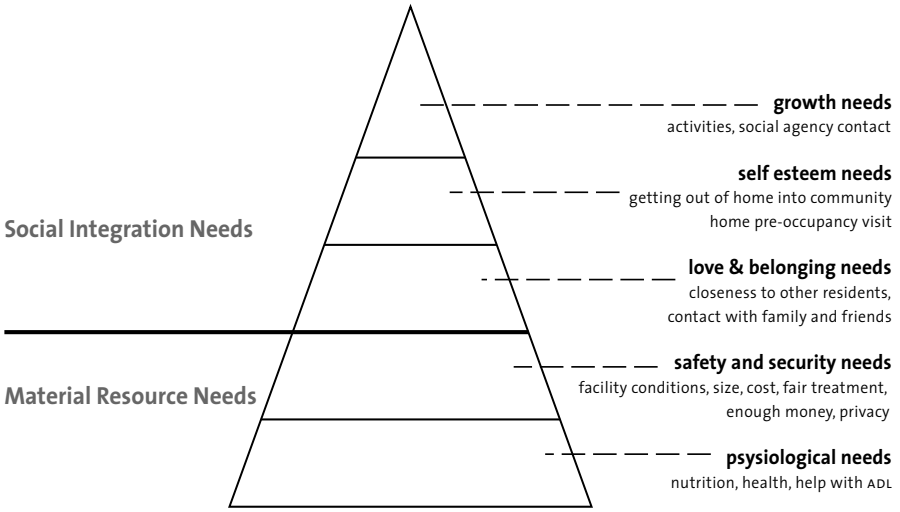
Faulk's board and care home hierarchy of needs

In 1988, Faulk introduced a hierarchical model of QOL factors relating to board and care homes for the elderly (see Figure 2). The model is based on Maslow's hierarchy of human needs (1968) and Tyne's (1985) adaptation of it to mentally handicapped people in residential settings. In Maslow's view, human beings strive to realize their inner potential, so-called *self-actualization*. Visualized as a pyramid, beneath self-actualization there are four other kinds of needs. From bottom to top, these are: physiological needs (food, water); safety needs; needs for belongingness and love; and esteem needs. People place a greater value on higher-order needs, but will only strive for those when lower-order needs are satisfied. Higher-order needs produce more desirable subjective results, such as more profound happiness (McAdams, 1994; Maslow, 1970). Tyne (1985) divided the various levels of Maslow's pyramid into two kinds of need-levels: the lower-level

resource needs (physiological and safety needs) and the higher-level needs for social integration. Faulk uses Tyne's ideas to formulate his board and care home hierarchy of needs (see Figure 2). He assumes that board and care residents will need assistance in meeting their *material resource needs* as well as their *social integration needs*. The level of QOL for these residents will thus be dependent on the degree to which they are able, with assistance, to meet those needs.

Faulk tested his model empirically by measuring the degree to which material resource needs and social integration needs were met, and operationalized the five categories of needs with resident-specific needs for which there was considerable policy and theoretical interest at that time (see Figure 2). His assumption that "*the more one settles for only meeting lower level resource needs, the less one influences QOL*" (1988, pp. 114), was supported by the data.

Figure 2. Faulk's Board and Care Home Hierarchy



From Faulk LE. Quality of life factors in board and care homes for the elderly: A hierarchical model. Adult Foster Care Journal 1988, 2, p. 104, © Human Science Press. Reprinted with kind permission of Human Science Press.

Criteria

1) COMPREHENSIVENESS AND UNIVERSALITY: As Faulk adapts Maslow's universal and comprehensive hierarchy to include the special needs of board and care residents, his approach meets criterion one. This is also made explicit in his statement that "what distinguishes board and care residents most from other persons is not that they have different needs, but that they require some assistance in meeting their own needs" (1988, pp. 102).

2) INTER-RELATEDNESS: In Faulk's approach QOL depends on the degree to which the residents are able, with assistance, to meet their material resource needs

and their social integration needs. The fulfillment of each need will contribute positively to QOL. According to Maslow, meeting needs starts with the lowest level, and when those needs are met, the next level is addressed. Clearly, this is a one-way direction ending in growth. The question remains what happens when a lower-level need is not met: does this influence the level of QOL, are the higher-level needs still important and achievable, have they become unattainable, or do they then no longer exist? This is crucial, because if meeting higher-level needs is highly important for achieving QOL, and if they can be met despite the fact that a lower-level need is not met, resident care policies may choose not to address a particular lower-level need but to instead target a higher need. Furthermore, Faulk does not elaborate on the needs within one level, which levels are interrelated and how they relate; the levels of the hierarchy need to be further developed.

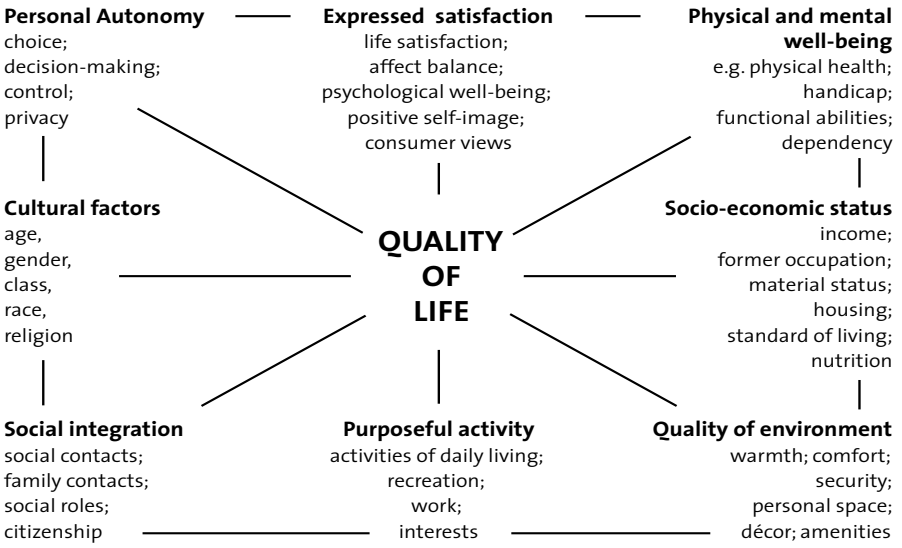
3) INDIVIDUAL PREFERENCES: It is not clear if and how there is room for individual variation in the levels of the hierarchy, for instance whether the relative importance of different needs can vary between persons.

Hughes' Quality of Life-network

Green and Cooper (2000) applied Hughes' framework for QOL in gerontology to the nursing home (1990), but did not adapt it. Therefore, this paper will discuss Hughes' framework itself.

Hughes aimed to identify the components of QOL that are central and universal. In her view, the concept of QOL is multidimensional and the definition of QOL may vary, depending on the type of research (e.g. theoretical, applied, policy), but QOL can not be reduced to a series of objectively defined standards, nor can it be encompassed entirely by the subjective satisfaction expressed by the individual (1990, see also George & Bearon, 1980). She proposes a network approach, *"an interacting system of factors, which together define and assess QOL"* (1990, pp. 54). She identified eight factors that can be linked to sub-systems: personal autonomy; expressed satisfaction; physical and mental well-being; socio-economic status; quality of the environment; purposeful activity; social integration and, lastly, cultural factors (see Figure 3). No clear definition of the eight factors is given, but it is stated that each factor contains a sub-system of related factors that have to be defined and translated into operational indices by the researcher. She gives examples of these sub-systems of related factors (Figure 3). All factors in the network are related directly or indirectly to one another. Their integration determines the level of QOL for an individual.

Figure 3. Hughes' Quality of Life Network



From Hughes B. Quality of Life. In: Peace SM, ed. Researching Social Gerontology: concepts, methods and issues. London: SAGE, 1990, p. 55, © SAGE Publishers. Reprinted with kind permission of Sage Publishing Ltd.

Criteria

1) COMPREHENSIVENESS AND UNIVERSALITY: Given Hughes' aim to identify the components of QOL that are central and universal as well as her opinion that the quality of a good life for elderly people cannot be considered to be intrinsically different to that of the rest of the population, criterion one appears to be met.

2) INTER-RELATEDNESS: Hughes places QOL in the center of a network of interacting factors that together define QOL (Figure 3), which suggests that these factors determine QOL. The question that remains, however, is: how? Moreover, although she states that factors can form sub-systems, the relationships are not clear.

3) INDIVIDUAL PREFERENCES: Although Hughes attaches importance to a person's entire life experience and the probability of common aspects in old people's lives, it is not clear how the individual aspects are involved.

Katz and Gurland's challenges to adaptation

In the book edited by Birren et al. (1991), Katz and Gurland wrote a chapter on the concept of holism, which proposes that the quality of the lives of older people is made up of an irreducible combination of three parts: 1) the elders themselves (i.e. their make-up in terms of body, mind and spirit), 2) their animate and inanimate environments, 3) their life experiences in space and time, and the

functions or powers created by the interwoven parts. They are of the opinion that, in order to understand the QOL of elders, one must understand the network of the combined parts, as the process of living is not explained by one of the parts alone. This network provides the *"structure within which the individual performs the required developmental tasks at various stages of life; and the degree of success with which tasks are performed, and crises met, spells the difference between good and impaired health"* (Bennett, cited in Katz & Gurland, 1991, pp. 340).

Katz and Gurland (Katz & Gurland, 1991; Gurland & Katz, 1997; Scheibel et al., 1992) regard QOL as an individual's ability to adapt and is explained by objective (observable) and subjective (internal state) features that are independent of each other. Intact QOL is regarded as emanating from adaptive responses, and impaired QOL from maladaptive responses. The severity of maladaptation is determined by its *intensity*, i.e. the level of impairment, and by it's *extensity*, i.e. the degree to which impairment pervades the elder's daily life. The execution of adaptive tasks is seen as the integration of skills, each of which can be arranged in a hierarchy reflecting an increasing potential for adaptation. The successive level of adaptability requires the lower-order skills to be intact. On the basis of previous research on (measurement instruments for) QOL they formulated 19 domains. The domains consist of *"distinctive challenges to adaptation, as well as sets of responses that reflect the elder's efforts to meet each challenge"* (Gurland & Katz, 1997, pp. 197), thereby focussing in particular on functional skills. The domains are inter-connected, and have to be taken into account in order to obtain a complete and authentic picture of QOL.

Criteria

1) COMPREHENSIVENESS AND UNIVERSALITY: Katz and Gurland apply the idea that QOL is a holistic phenomenon to the elderly (1991), making reference to the work of Bennett and Cath. Therefore, it can be concluded that they founded their work on the concept of comprehensive QOL applying to human beings in general.

2) INTER-RELATEDNESS: It remains unclear how the domains, i.e. adaptive tasks, relate to the hierarchy of skills, and whether these skills are also components of QOL. As a consequence, it is impossible to determine what the effects of not completing a certain adaptive task are on the other domains and on the level of QOL.

3) INDIVIDUAL PREFERENCES: When formulating a specific definition of QOL in dementia (Gurland & Katz, 1997), Katz and Gurland apparently recognized that the concept of QOL may vary across specific population groups. Whether it also varies between individuals is not clear.

The QOL approach based on the theory of Social Production Functions

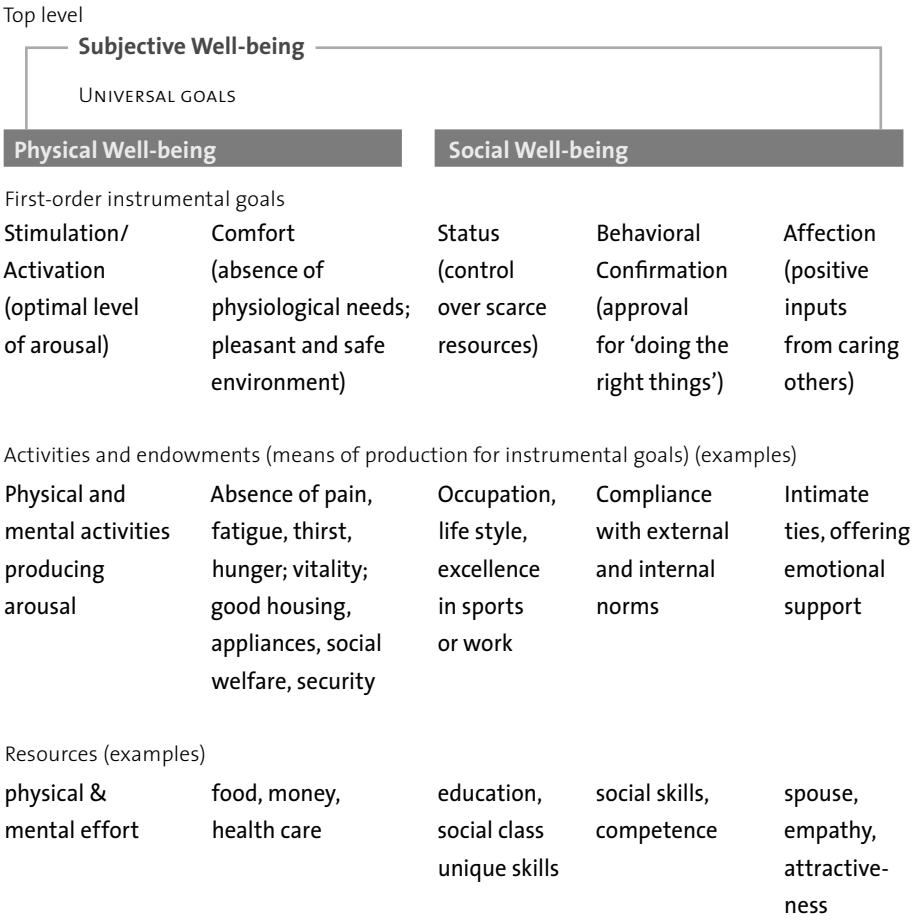
Two publications that were identified focus on the theory of social production functions (the SPF theory) as a comprehensive theory for QOL (Kempen et al. 1998; Ormel et al., 1997). Initiated by Lindenberg (1986; 1996), regarding human beings in general, Ormel et al. (1997; Kempen et al., 1998) used the theory as the conceptual framework in their survey of elderly people in the community, Steverink applied the theory to a population of frail elderly people (2001), as well as to successful aging in general (Steverink, Lindenberg & Ormel, 1998).

According to the SPF theory (Lindenberg 1986, 1996), every individual's behavior is aimed at being well. An individual strives to gain well-being through reaching particular universal and more specific goals, within the constraints she faces. The theory proposes a hierarchical approach to goals (see Figure 4). From bottom to top, each level in the hierarchy is instrumental to the level above. High in the hierarchy, the goals are assumed to be universal, i.e. referring to all human beings. It is assumed that subjective well-being (i.e. overall QOL, or psychological well-being) (Ormel, Lindenberg, Steverink & Verbrugge, 1999) is the ultimate and overall goal for an individual and is the result of the realization of physical and social well-being. The more social and physical well-being that can be achieved, the higher the level of overall QOL will be. Physical and social well-being are considered to be universal goals that are aimed for and achieved by realizing other, lower level goals. On the first level below the universal goals there are five first-order instrumental goals. Two are formulated for physical well-being: stimulation is a pleasant amount of stimulation and activation; comfort refers to the satisfaction of basic physical needs, a safe environment and the absence of health complaints. There are three first-order goals for social well-being: affection refers to being loved as a person by oneself and by others; *behavioral confirmation* refers to doing the right thing in the eyes of oneself and others; and *status* is the accomplishment of appreciation from oneself and others as a consequence of having certain positive distinctive characteristics.

All goals in the hierarchy are achieved by using resources, which are considered as things that people have and do to achieve goals. Lower in the hierarchy, when goals have been achieved, they can subsequently be used as resources to achieve higher goals. However, resources are held to be scarce, which implies that the individual is limited in achieving her goals. Steverink (2001) described that with increasing age, an individual is probably confronted with losses, and is not always able to maintain all five first-order instrumental goals. A goal that is costly and depends on many or specific resources will be discarded first. By substituting (i.e. compensating for) lost resources and instrumental goals with other, as yet available resources or attainable goals, an individual may still be able to achieve a high level of physical and social well-being. Physical and social well-being are not entirely inter-changeable; it is assumed that a certain amount of each is neces-

sary in every individual. In recent years, several studies have provided empirical evidence to support the SPF theory (Steverink, 2001; Van Bruggen, 2001; Van Eijk, 1997; Nieboer, 1997).

Figure 4. Quality of Life hierarchy of the SPF theory



From Ormel J, Lindenberg S, Steverink N, Verbrugge L. Subjective well-being and social production functions. Social Indicators Research 1999, 46, p. 67, © Kluwer Academic Publishers. Reprinted with kind permission of Kluwer Academic Publishers.

Criteria

1) Comprehensiveness and universality: As the SPF theory is a comprehensive approach to the QOL of human beings in general, the first criterion is met.

2) Inter-relatedness: In the SPF theory, overall QOL, or subjective well-being, is the ultimate goal of human behavior, and is at the top of a hierarchy of goals ((sub-)dimensions) which are instrumentally related from bottom to top, which explains the contribution of the (sub-)dimensions to overall QOL. With regard

to their inter-relatedness, the SPF theory states that personal resources can be used to achieve multiple (first-order) goals and that both resources and goals are interchangeable and can be used to compensate for losses of other resources or goals, although people do need a minimum amount of both physical and social well-being.

3) INDIVIDUAL PREFERENCES: overall QOL, physical well-being and social well-being are universal goals. However, the lower they occur in the hierarchy, the more specific and idiosyncratic, i.e. individually variable, the goals and resources of an individual will be. The SPF theory assumes that, although the aim is to achieve all five first-order goals, an individual will focus on the goals that can still be achieved when it is no longer possible to achieve all the goals. Therefore, the first order goals may, to a certain extent, also vary across individuals.

Ball's QOL domains

Ball et al. (2000) interviewed residents and observed life in seventeen assisted living facilities in order to conceptualize QOL in such facilities. They support the consensus of opinion that QOL is a multidimensional construct with both subjective and objective components. Based on empirical research, Ball et al. identified 14 domains of QOL. The domains represent the combined internal perceptions of residents with regard to what is important to them. Considerable differences were found between residents with regard to the personal significance of each domain. QOL evolved as a subjective, complex and multidimensional construct with interacting and overlapping domains. Ball et al. mention a clear primacy of five domains for most residents: psychological well-being; independence and autonomy; social relationships and interactions; meaningful activities; and care provided by the facility.

Ball et al. accept Lawton's view that *psychological well-being* is the ultimate outcome and include in this domain the residents' general satisfaction with life in the facility and their emotional states. *Independence* refers to the residents' ability to take care of their own needs. Ball et al. found that independence enhanced the residents' self-esteem, helped them to maintain their remaining functional ability, and provided them with meaningful activity. *Autonomy* refers to the residents' control over their everyday environment and choice of options that are significant for the individual. With regard to *social relationships*, for most residents the relationships with their family and in particular with their children, were vital to their QOL. *Meaningful activities* were also a key component of the residents' QOL, and what activities were found to be meaningful varied between individual residents. The positive evaluation of the *care provided by the facility* depended on the attitude of the caregivers.

A key factor in whether residents defined their lives as having quality was the quality of fit between the resident and the facility's social and physical envi-

ronment, more specifically, between the resident and the structure and process of the care provided, with which most domains had an obvious relationship.

Criteria

1) Comprehensiveness and universality: Ball et al. aim to be comprehensive, but their method (asking the residents), does not ensure that all important aspects were identified. Furthermore, it is not based on the QOL of human beings in general. This is unfortunate, because it is therefore not clear how residents of residential homes differ from other people, so possible changes or differences that apply to them cannot be addressed.

2) Inter-relatedness: Ball et al. only address the relationship of psychological well-being to QOL. They follow Lawton in his approach, i.e. that psychological well-being is both a domain of QOL and the ultimate outcome in an open causal model. Yet, it is still not clear how this 'central outcome' contributes to QOL and relates to other (sub-)dimensions. Although Ball et al. found that most domains had an obvious relationship with the social and physical environment of the facility, these findings do not explain how each domain relates to the others.

3) Individual preferences: In aiming to do justice to individual preferences, Ball et al. started with individual views on important domains of QOL. Yet, they subsequently elaborate on five domains that were considered to be important by most residents, thereby moving away from the perspective of the individual.

In Table 1 the six frameworks are compared, and it can be concluded that they differ with regard to meeting the predetermined criteria. Only the SPF theory meets all three criteria. The framework of Ball et al. is not based on assumptions of OQL for human beings in general, so, in our view, it is fundamentally flawed. The other four frameworks are not flawed, but they lack clarity on criteria 2 and 3, and need to be further developed before they can be considered useful as a conceptual basis for QOL-enhancement. The framework of the SPF theory, according to the three criteria applied, appears to be the most suitable as a basis for understanding QOL, to provide nursing home staff with tools to enhance QOL, and eventually to serve as a basis for the development of guidelines for QOL-enhancement. The possible implications of this theory, when applied to nursing home residents, are discussed below.

Understanding the QOL of residents in terms of the QOL approach of the SPF theory

Following the SPF theory, QOL would increase with the number of first-order instrumental goals (well-being goals) that are achieved. In other words: the more comfort and stimulation (for physical well-being) and the more affection, behavioral confirmation and status (for social well-being) residents are able to realize,

Table 1. Comparison of the frameworks

Criteria	Lawton	Faulk	Hughes	Katz & Gurland	SPF-theory	Ball et al.
1. Comprehensiveness	+	+	+	+	+	–
2. Inter-relatedness	–	+/–	–	–	+	–
3. Individual preferences	+/–	–	–	–	+	–

+ : framework meets criterion
+/- : framework does not meet the criterion entirely
– : framework does not meet criterion

the higher their level of QOL will be. At this point, in view of the impaired cognitive status of many nursing home residents, it should be noted that the realization of one's well-being is, in terms of the SPF theory, not necessarily a conscious process but related to an intrinsic motive to strive for improvement of one's condition (Lindenberg, 2001). This motive is assumed to apply to all human beings.

Through the mechanism of *substitution* between resources and goals, the level of QOL can still be relatively high, even when people can no longer realize one or more of the five well-being goals. Loss of status, for instance, can be substituted by putting more effort into achieving the other two goals of social well-being, i.e. affection and behavioral conformation, without losing much QOL. Furthermore, the SPF theory is not only explicit about the mechanism of substitution (and thus about the relationships between (sub-)dimensions of QOL), it also assumes a *patterned change* in substitution processes when people lose resources due, for instance, to aging processes (Steverink et al., 1998). It is predicted that status is probably the first goal that has to be discarded. When further losses occur, stimulation and behavioral confirmation will be the next to go. The goals of comfort and affection can be maintained relatively easily, although eventually these may also become threatened. When the last remaining resources for comfort and affection become threatened, QOL is seriously endangered, and people will do everything in their power to prevent further losses. This stage is called the *critical phase* (Steverink, 2001).

Nursing home residents have, in general, lost many physical and social resources. From the SPF theory and its sub-theory of the critical phase it can be derived that care-providers who aim to optimize the QOL of nursing home residents must at least provide a satisfactory level of comfort and affection. However, the QOL of residents would be enhanced if attention were also paid to stimulation, behavioral confirmation and status. So, nursing home residents will perceive higher levels of QOL if they not only realize comfort and affection, but also stimulation and behavioral confirmation, and even more so when they are able to realize status.

When relating the theoretical insights of the SPF theory to everyday life in the nursing home, the five goals of well-being appear to be compatible with and, to some degree, already considered in nursing home practice. The patterned change prediction that comfort and affection can be maintained the longest seems to be quite plausible. Comfort and affection are the ultimate care-targets in nursing home care. *Comfort* can be considered as the basis of care: in the eyes of the nursing home staff, the first priority is to make the resident comfortable. In times when the workload is very heavy, comfort is the most paramount, and sometimes the only focus of care that must be maintained at all costs. *Affection* is also important, and is a primary care-target in the nursing home, especially when a resident's functioning has deteriorated to the extent that being kind – sometimes only through the touch of a hand – may be the only means of making contact. *Stimulation* and *behavioral confirmation* are, for instance, represented in the emotion-oriented care-approaches to demented residents, including validation (Feil, 1989, 1992), reminiscence (Rossaert, 1989), sensory activation or 'snoezelen' (Achterberg, Kok & Salentijn, 1997), and integrated emotion-oriented care (Dröes, 1991; Finnema, Dröes, Ribbe, van Tilburg, 2000). In these care-approaches, an attempt is made to link up with the experiences and perceptions of the person with dementia. Expressing affection and stimulating the resident in reliving, structuring, integrating and exchanging memories (reminiscence) or various sensory perceptions and experiences (snoezelen), are common, and highly significant. Moreover, in the interactions with the residents, behavioral confirmation through endorsing their behavior and supporting their initiatives is an important target, especially in validation and integrated emotion-oriented care (Finnema et al., 2000). Furthermore, the assumption that stimulation is important is in line with the tradition that is upheld in nursing home care, i.e. to stimulate the resident and to provide pleasant activities, for instance by employing occupational and recreational therapists (Green & Cooper, 2000; Teri & Logsdon, 1991). *Status* is difficult to uphold, because many of its resources are of a societal nature. However, being different from other residents and maintaining a personal identity is still feasible, and possibly very important for a resident. For instance, a resident who had been a professional ballet dancer appeared to feel much happier after enlarged photographs of her dancing had been hung on the walls of her ward. Therefore, status can also be a target in the optimization of QOL in nursing home residents. In sum, nursing home practice appears to have important links with the theory of SPF. Nevertheless, the advantage of using the framework of the SPF theory is that it systematizes these practices into a whole of QOL-enhancing procedures, and thus provides insight into which QOL goals are already targeted and which still need to be addressed. Moreover, it can be used as a heuristic to find new ways of helping residents to realize the goals of well-being.

Nursing home residents have lost resources in various (sub-)dimensions, and an important question is: how do they succeed in realizing a high level of QOL? By knowing what resources are left it is possible to gain insight into the potentials and abilities that a resident (still) has to realize QOL and thus contribute effectively to enhancing that QOL. Instead of focussing only on problems and disabilities, the care-targets should also include the resident's specific, vital resources. Given the prediction that not only comfort and affection, but also behavioral confirmation, stimulation and status are essential when aiming for insight into and optimization of QOL, the focal point should be achievement of these goals of well-being.

According to the SPF theory, the people in the environment of the residents are important sources from which they can obtain comfort, affection, stimulation, behavioral confirmation and status. Nursing home staff can help residents to achieve their goals by participating extensively in providing them with the necessary resources. An important implication of this mechanism is that the care that is provided must be optimal in order to contribute effectively to QOL-enhancement. When the nursing staff does not have enough time to assist them in this way, the residents are in danger of having a low level of QOL. This applies, in particular, to residents who have lost almost all their personal resources for realizing their own well-being, for instance those who are severely demented.

Discussion

In this paper, the aim was to find a framework for QOL in nursing home residents that explains what QOL is and how a high level of QOL can be achieved, and can therefore serve as a basis for QOL-enhancement in the nursing home setting. It was argued that a QOL framework is suitable for that purpose if it meets at least three criteria. A search in the literature yielded several QOL frameworks applied to elderly nursing home residents (or frail elderly people), which were briefly described and evaluated. The framework that appeared to meet all three criteria, the SPF theory, was discussed in detail.

Some points of discussion and suggestions for further research must be mentioned. The first point concerns the completeness of the three predetermined criteria, which were formulated specifically to evaluate the suitability of each framework as a basis for QOL-enhancement and the possible development of guidelines for nursing home staff. As such, they should be considered as the minimal requirements of a framework suitable for that purpose. Nevertheless, there may be other relevant criteria, for instance pertaining to the empirical basis of the framework. These were not included, as they could have led to the exclusion of new frameworks that may be promising but still need empirical testing. However, an empirical test of the validity of any framework is the only

test that can provide evidence of its tenability and suitability to function as a basis for guidelines for QOL-enhancement.

A second point, which is closely related to the first, is the need for more empirical research. So far, the SPF theory has been applied empirically to frail elderly people, but not specifically to the nursing home population. Therefore, it should be investigated whether the hypotheses about QOL that follow from the theory do, in fact, apply to the nursing home population. Thus, it should be empirically established whether residents do, indeed, experience more subjective well-being when they have a higher level of affection, behavioral confirmation, status, comfort and stimulation, or whether the loss of certain goals can be substituted by other goals. Moreover, as the different causes of the residents' conditions lead to highly varied resident characteristics, it should be investigated whether there may be specific sub-groups (e.g. demented residents) for which the basic assumptions of the SPF theory are no longer valid. It is possible that for some specific groups the achievement of certain first-order instrumental goals (e.g. status or stimulation) no longer contributes to QOL. This aspect should be investigated, as it may have implications for the validity of this theory as a basis for QOL- enhancement in the nursing home setting.

Finally, further research is needed with regard to the selection or development of appropriate measurement instruments. These instruments should closely fit the framework in order to test it adequately. Moreover, it should be investigated, in close collaboration with the nursing home staff, how the components of the framework can be measured most appropriately (directly or indirectly; objectively or subjectively; by observing behavior or interpreting other known facts; etc.).

Summarizing, it appears that the SPF theory can be used as a suitable conceptual basis for understanding QOL in the nursing home, and can subsequently form the basis for the development of guidelines for QOL-enhancement in nursing homes. When it can be shown empirically that this framework can, indeed, improve our understanding of QOL in nursing home residents, this will open the door to individually tailored QOL-enhancement interventions – based on the same framework – to be developed in the format of guidelines. A special point of interest in the development of guidelines would be the extent to which others, e.g. nursing home staff or the resident's children, can help the resident to effectively realize a high level of QOL. Most residents are dependent on the nursing home staff for the provision of important resources for QOL. Moreover, they may be unable to express or even determine what really is important to them. More insight into the QOL of nursing home residents, how it can be improved, and its implications for the quality of care, will increase the effectiveness of approaches to the care, and thus the QOL of residents.

Reliability and validity of MDS scales for Activities of Daily Living, cognition and depression

Chapter 3 is a revision of Gerritsen, D. L., Ooms, M. E., Steverink, N., Frijters, D., Bezemer, D., & Ribbe, M. (2004). Drie nieuwe observatieschalen in het verpleeghuis: schalen uit het Resident Assessment Instrument voor Activiteiten van het Dagelijks Leven, Cognitie en Depressie. Tijdschrift voor Gerontologie en Geriatrie, 35, 55-64.

Chapter 3

Reliability and validity of MDS scales for Activities of Daily Living, cognition and depression

The most important goal for nursing home staff is to provide comprehensive, individualized care, thereby contributing to the physical and psychosocial well-being of the resident. However, this goal is not easily achieved, since it implies that care-providers must be familiar with many aspects of the residents' functioning and well-being, and also know how to optimize them (see Chapter 2). Moreover, the provision of adequate care is hindered by the fact that many residents are not (fully) able to communicate their needs. A useful aid for good care-giving would thus be a comprehensive assessment instrument that is not dependent on verbal communication with the residents.

The most extensively tested and evaluated comprehensive instrument is the Minimum Data Set (MDS) of the Resident Assessment Instrument (RAI), a set of 120 items, mainly observational, covering the resident's functional, medical, psychosocial and cognitive status (Holtkamp, 2003; Morris et al., 1990). It was originally developed in the United States, and has subsequently been introduced in various countries, including the Netherlands. The MDS is part of the Resident Assessment Instrument (RAI) (Frijters et al., 2001). The RAI is an automatized client-monitoring system that supports the care planning process. Every quarter, by means of a completed MDS, it provides a comprehensive overview of the residents' functioning, and subsequently signals the possible presence of specific problems. Also, by means of standardized analyses-protocols, it provides a grounded and structured approach for investigating the possible problems that were signaled, and for incorporating these in the care plan.

Based on the MDS items, measurement scales for various aspects of resident status have subsequently been developed. These enable care-providers to monitor an individual resident's status. It facilitates the optimization of nursing home

care and enables comparisons to be made between nursing homes and even across countries (Ribbe et al., 1997). Nevertheless, measurement scales are only beneficial if their psychometric abilities are adequate. The reliability of most of the MDS items and the validity of the MDS Cognitive Performance Scale (CPS) have been established (Sgadari et al., 1997; Morris et al., 1994; Hartmaier, Sloane, Guess, Koch, Mitchell, & Philips, 1995; Gruber-Baldini, Zimmerman, Mortimore & Magaziner, 2000). However, the psychometric properties of the MDS Activities of Daily Living Self Performance Hierarchy (ADL-SPH) have not yet been studied since its introduction (Morris, Fries, & Morris, 1999). Moreover, the validity of the MDS Depression Rating Scale (DRS) (Burrows, Morris, Simon, Hirdes & Philips, 2000) has recently been questioned (Anderson, Buckwater, Buchanan, Maas, & Imhof, 2003). The most important reason for this study is that the psychometric properties reported by those who developed the scales are almost all based on assessments made by research trained nursing staff (Gruber-Baldini et al., 2000), whereas in daily nursing home practice the licensed practical nurses who provide daily care make the assessments. This may lead to different psychometric properties. The objective of this chapter was to determine the reliability and validity in daily nursing home practice of the ADL-SPH, the CPS and the DRS.

Methods

Data-collection

At the time of data-collection, 10 out of the 340 nursing homes in the Netherlands worked with the RAI, and 9 of these were willing to participate in the study. For analysis of the reliability and validity of the scales, data were collected on a maximum random sample of 30 residents per nursing home over a period of 3 months, with an equal distribution of residents with mainly physical handicaps (from so-called 'somatic' units) and mainly dementia syndromes (from so-called 'psychogeriatric' units). After the research proposal had been approved by the Medical Ethics Committee of the Vrije Universiteit Medical Center, the participants had been recruited, and written informed consent was obtained from each participant or his/her representative, the data-collection commenced in the participating nursing homes.

To determine the intra- and inter-rater reliability of the MDS scales, three MDS assessments were made by nurses who provided daily nursing care for the residents in question. They had all previously received training in the MDS protocol. First, one nurse completed an MDS, and after at least one week, but within one month, the same nurse completed a second MDS to determine intra-rater reliability. The intra-rater reliability, also called the test-retest reliability, is the agreement between multiple assessments made by one rater. The inter-rater reliability is the agreement between multiple assessments made by two or more raters. To calculate inter-rater reliability a third MDS assessment was made dur-

ing the same month by another nurse. This procedure was continued until 152 residents had been assessed. Only one MDS-assessment was completed for the rest of the participating residents.

To determine the validity of the MDS scales, a number of other measurement instruments were included in this study for comparison with the MDS scales; these will further be referred to as 'comparison measures'. The choice for a particular measure was primarily based on its known reliability and validity in the Dutch nursing home population, and if no such instrument was available, an instrument that had been used before in research in Dutch nursing homes was chosen. To prevent overburdening the nursing staff, only one observational comparison measure was applied per aspect of functioning. The measures used are described in the section 'Instruments'. The nursing staff made the observational assessments, while the principal investigator administered the interviews (self-report questionnaires and cognitive tests). The completeness of the data obtained from the interviews depended on the resident's cognitive and physical abilities, and willingness to answer all the questions. To assure the validity of cross-sectional comparisons, all scales for each resident were assessed within the same four-week period.

Measurement instruments

Activities of Daily Living

The MDS-ADL Self-Performance Hierarchy (ADL-SPH) (Morris et al., 1999) is an observational scale for ADL-dependence that measures resident self-involvement in the personal activities of daily life (see Appendix 2). It includes 4 of the ADL items of the MDS, each with 4 response categories, and is scored according to a decision tree with 7 scale categories, ranging from 0 (independent) to 6 (totally dependent). When first introduced, its reported psychometric properties were kappa values of the items, ranging from .87 to .94 (inter-rater reliability) and an internal consistency (Cronbach's alpha) of .90 (Morris et al., 1999).

For comparison, the Modified Barthel Index (MBI) was used (Fortinsky, Granger & Seltzer, 1981). The MBI is an observational instrument with 15 items on help needed in performing the activities of daily living. The 4-level response category introduced by Fortinsky et al. (1981) is a modification of the original Barthel Index designed by Mahoney and Barthel (1965), and is widely used in rehabilitation studies and in geriatric populations (Zijp, van den Bosch, & van Hezik, 1995; Dittmar & Gresham, 1997). The index ranges from 0 (total dependence) to 100 (total independence). Its internal consistency in this sample was .80.

Cognition

The Cognitive Performance Scale (CPS) is a 7-point hierarchical observational scale that rates cognitive impairment from 0 (intact) to 6 (very severe

impairment) (Morris et al., 1994) (see Appendix 2). The CPS consists of 7 items, and is scored according to a decision tree. The reported Cronbach's alphas of the CPS range from .70 to .88 (Morris et al., 1995; Gruber-Baldini et al., 2000). Its sensitivity and specificity against the MMSE were .94 (Hartmaier et al., 1995) and an earlier established correlation with the MMSE was .65 (Gruber-Baldini et al., 2000). Snowden and co-workers (1999) found that the CPS had a larger effect size than the MMSE.

For comparison, two measures were applied, the Mini Mental State Examination (MMSE), which is a test for cognition, and the Bedford Alzheimer Nursing Severity Scale (BANS-S), which is an observational scale. The MMSE has scores ranging from 0 (very severe impairment) to 30 (no cognitive impairment) (Folstein, Folstein & McHugh, 1975; Kempen, Brilman & Ormel, 1998). Internal consistency in this sample was .89.

The BANS-S has been found to determine the severity of dementia in cognitively severely affected residents, including those with types of dementia other than Alzheimer's disease (Volicer, Hurley, Lathi & Kowall, 1994; Bellelli, Frisoni, Bianchetti & Trabucchi, 1997; Van der Steen, Ooms, Van der Wal, Ribbe, 2002). It not only measures cognitive functioning, but also functional deficits and pathological symptoms. It consists of 7 items, and the sum scores range from 0 (no impairment) to 21 (complete impairment). In this study, the BANS-S was used to assess residents in psychogeriatric units only. Its internal consistency in this sample was .75.

Depression

The MDS Depression Rating Scale (DRS) is an observational scale, based on MDS items, which can be used to screen for depression (Burrows et al., 2000). The DRS consists of 7 MDS items that are summed (see Appendix 2). The scores range from 0 (no depressive behavior) to 14 (frequent depressive behavior). The internal consistency (Cronbach's alpha) when it was developed was .75 in the derivation sample and .71 in the validation sample. Its sensitivity against a psychiatric diagnosis of depression was 91% (Burrows et al., 2000). In a recent validity study the internal consistency of the DRS was .68, and its correlations with the Geriatric Depression Scale (GDS) and the Hamilton Depression Rating Scale were .19 and .24 respectively (Anderson et al., 2003).

For comparison, the GIP-sad behavior, the GDS and the Depression List (DL) were applied. The GIP-sad behavior (Verstraten & Van Eekelen, 1987; Verstraten, 1988) is a sub-scale of the Behavior Observation Scale for Geriatric Inpatients (GIP). The GIP is widely used in nursing homes in the Netherlands and addresses social, cognitive, psychomotor and emotional 'behavioral types' in elderly residents. It was especially developed for cognitively impaired residents, but is also suitable for physically frail residents (Verstraten, 1988). The 6-item GIP-sad behavior (GIP-

s) measures behaviors of elderly people in intramural care settings that express sadness, unhappiness, and anxiety. Sum-scores range from 0 (no sad behavior) to 18 (frequent sad behavior). When first published, internal consistency (Cronbach's alpha) was .84, and inter-rater reliability (Pearson's r) was .74 (Verstraten & Van Eekelen, 1987). In a validation study, internal consistency was .86, average inter-rater reliability of the items (Cohen's weighted kappa) was .43, (De Jonghe, Kat & De Reus, 1994). In the present sample, the internal consistency was .79.

The GDS is a self-report screening instrument for the elderly (Brink et al., 1982; Kok, 1994). It consists of 30 dichotomous questions, and the scores range from 0 (no depressive complaints) to 30 (many depressive complaints). As its reliability in people with an MMSE score of less than 15 is questionable (McGivney, Mulvihill & Taylor, 1994), the GDS was only administered if the MMSE score was equal to or above 15. Its internal consistency in this sample was .91.

The DL is a Dutch self-report screening questionnaire for depression, especially developed for people with dementia (Diesfeldt, 1996; 1997). It consists of 15 keywords that are presented on cards, one by one, accompanied by a simple question. For instance, a card with 'satisfaction' printed on it is accompanied by the question 'do you feel satisfied?'. Sum scores range from 0 (no depressive complaints) to 30 (many depressive complaints). The DL was administered to residents with an MMSE score of less than 15. In psychometric research, the reported internal consistency of the DL was .82, but further psychometric properties have not yet been reported (Diesfeldt, 1997). The internal consistency in this sample was .79.

Analyses

Intra-rater and inter-rater reliability of the items of the MDS scales were determined by calculating Cohen's squared weighted kappa (Cohen, 1968). Kappa was determined over the entire group and for residents from 'somatic' (SOM) and 'psychogeriatric' (PG) units separately. The intra-rater and inter-rater reliability of the MDS scales were assessed with the intraclass correlation coefficient (ICC) by means of the 'reliability' procedure in SPSS (version 10.1), establishing absolute agreement (Shrout & Fleiss, 1979). In this study, intra-rater ICC was calculated (the comparison of the sum scores of two scale-assessments by one rater) as well as the inter-rater ICC (the comparison of the sum scores of two scale-assessments by two raters). Internal consistency was determined with Cronbach's alpha (Cronbach, 1951).

Concurrent validity of the scales was also addressed for the group as a whole and for SOM and PG residents separately. Spearman's rho was used to calculate the correlations between the comparison measures and the MDS scales, and scatter diagrams provide information on possible floor- and ceiling effects.

If necessary, scales were recoded so that a high score indicated severe impairment.

Results

Sample description

Of the 300 residents who were invited to participate, 237 gave their informed consent. For 227 of these, at least one MDS assessment was completed. For 152 residents, a second assessment was made by the same nurse and a third by another nurse. Table 1 shows the sample characteristics of the 227 assessed residents. These are compared to the characteristics of residents in the VURAI database. The VURAI database is a database managed at the Vrije Universiteit Medical Center, which contained at the time of the study approximately 6000 MDS assessments of some 1900 residents of the 10 nursing homes working with the RAI in the Netherlands. Compared to the VURAI database, the present sample contained more women, and the scores on the three MDS scales were somewhat lower, indicating less disability.

Reliability

The Landis and Koch classification (1975) was used to interpret the kappa results (.00 – .20 = slight, .21- .40 = fair, .41 – .60 = moderate, .61 – .80 = substantial, and .81 – 1.0 = almost perfect). This classification is conventionally also used for ICCs (Montgomery, Graham, Evans & Fahey, 2002). Cronbach's alpha is considered to be fairly good if higher than .70, but should not be higher than .90 (Streiner & Norman, 1995). The mean inter-item correlation is considered to be good if its values are between .20 and .50. Higher values suggest item-redundancy.

The mean intra-rater kappa values of the ADL-SPH items were almost perfect in the total group, as well as in both sub-groups, and the inter-rater kappas were substantial. Intra-rater and inter-rater reliability of the scale (ICCs) were very high, and internal consistency was also very good. The mean inter-item correlation of the scale was too high (see Table 2 for exact values).

The mean intra-rater kappa values of the CPS items were almost perfect in the total group, as well as in sub-groups, and inter-rater kappa values were substantial. Intra-rater and inter-rater reliability of the scale were high to very high for the total group and also for SOM residents, but for PG residents the ICCs were lower. Internal consistency was fairly good, but lower in PG residents, with a good mean inter-item correlation.

For the DRS, mean intra-rater and inter-rater kappa values of the items were moderate, but in PG residents the kappa of some of the items was only fair. Intra-rater and inter-rater reliability of the scale were moderately high, but again somewhat lower in PG residents. Internal consistency was good, with good mean inter-item correlation.

Table 1. Sample Characteristics

	Sample			VURAI-DB
	SOM residents[1]	PG residents[2]	Total	Total
Demographic characteristics				
N	117	110	227	1915
% women	70.9	84.7	78.0	72.3
mean age (range)	77.3 (52-100)	82.6 (56-99)	79.9 (52-100)	79.9 (15-102)
Mean (SD) MDS scales				
ADL-SPH	3.32 (1.64)	3.34 (1.71)	3.33 (1.67)	3.55 (1.67)
(Range: 0 – 6)	N=117	N=110	N=227	N=1915
CPS	1.62 (1.85)	3.80 (1.60)	2.68 (2.04)	3.03 (1.96)
(Range: 0 – 6)	N=116	N=110	N=226	N=1915
DRS	1.80 (2.36)	2.48 (2.76)	2.13 (2.58)	2.25 (2.65)
(Range: 0 -14)	N=116	N=110	N=226	N=1913
Mean (SD) comparison measures				
GBI	53.11 (24.40)	51.82 (25.93)	52.48 (25.11)	
(Range: 0 -100. alpha[3] = .80)	N=110	N=106	N=216	
MMSE	16.78 (9.40)	6.59 (5.80)	12.00 (9.40)	
(Range: 0 – 30. alpha = .89)	N=106	N=94	N=200	
BANS-S	XXX	14.92 (4.59)	XXX	
(Range: 0 – 21. alpha = .75)		N=106		
GIP-S	4.58 (3.71)	3.36 (3.09)	3.97 (3.46)	
(Range: 0 – 18. alpha = .79)	N=106	N=106	N=212	
GDS	11.57 (7.38)	8.90 (6.76)	11.37 (7.45)	
(Range: 0 – 30. alpha = .91)	N=65	N=7	N=72	
DL	7.91 (5.45)	7.56 (4.86)	7.71 (4.81)	
(Range: 0 – 30. alpha = .79)	N=29	N=62	N=91	

1 SOM residents: residents with mainly physical handicaps, from somatic units
2 PG residents: residents with mainly dementia syndromes, from psychogeriatric unit
3 Cronbach's alpha

Table 2. Intra- and inter-rater reliability of items (Kappa) and scales (ICC) and internal consistency (Alpha), for the total group and for residents of somatic (SOM) and psychogeriatric (PG) units separately

	ADL-SPH	CPS	DRS
Intra-rater Kappa, mean of scale-items (range)			
Total group (N=146-154)	.86 (.75-.90)	.87 (.83-.90)	.51 (.38-.61)
SOM (N=79-86)	.87 (.72-.93)	.83 (.70-.93)	.60 (.43-.83)
PG (N=67-69)	.84 (.78-.92)	.81 (.69-.87)	.42 (.22-.55)
Inter-rater Kappa, mean of scale-items (range)			
Total group (N=146-151)	.80 (.66-.88)	.78 (.77-.80)	.50 (.43-.62)
SOM (N=80-84)	.77 (.65-.87)	.68 (.54-.77)	.52 (.37-.68)
PG (N=64-68)	.82 (.66-.90)	.73 (.57-.86)	.47 (.30-.68)
Intra-rater ICC[1] of scale (confidence interval)			
Total group (N=138-151)	.81 (.75-.86)	.85 (.80-.89)	.73 (.65-.80)
SOM (N=74-82)	.86 (.79-.91)	.88 (.82-.92)	.80 (.71-.87)
PG (N=64-69)	.77 (.65-.85)	.68 (.53-.79)	.66 (.50-.77)
Inter-rater ICC of scale (confidence interval)			
Total group (N=137-151)	.83 (.77-.87)	.80 (.74-.85)	.71 (.62-.78)
SOM (N=76-84)	.82 (.73-.88)	.78 (.68-.85)	.71 (.59-.81)
PG (N=61-67)	.84 (.75-.90)	.67 (.52-.79)	.69 (.54-.80)
Cronbach's alpha (miic[2])			
Total group (N=225-227)	.84 (.60)	.74 (.48)	.73 (.28)
SOM (N=116-117)	.81 (.54)	.70 (.43)	.76 (.32)
PG (N=109-110)	.87 (.65)	.63 (.32)	.70 (.25)

1 ICC = Intraclass Correlation Coefficient
2 miic = mean inter-item correlation

Validity

As Table 3 shows, Spearman's rho for the ADL-SPH and the MBI was high in the total group as well as in subgroups, although the correlation for PG residents was lower. The scatter diagram did not point to floor- or ceiling effects (not shown). The correlation of the CPS with the MMSE was high, but lower for PG residents. The scatter diagram of CPS with MMSE showed there may be a ceiling-effect of the MMSE (see Figure 1a). In other words: residents whose scores indicated maximal impairments on the MMSE may still have had differentiating scores on the CPS. The correlation coefficient of the BANS-S (only used for PG residents) and the CPS was lower than the similar correlation coefficient of the MMSE.

The scatter diagram indicated a floor effect of the BANS-S. Residents who scored zero on the BANS-S (no impairment) seem to have had differentiating scores of mild to moderate impairment on the CPS (see Figure 1b). For the DRS the correlation with the GIP-S was moderate in the total group and PG-residents, and substantial in SOM-residents. The correlation with the GDS was substantial. The GDS was administered only in residents with an MMSE-score equal to or higher than 15, which resulted in only 7 PG residents having a GDS-score. The relationship between DRS and GDS thus actually pertains to SOM-residents. The correlation of the DL and the DRS was very low, in the total group as well as in both subgroups. The scatter diagrams did not show floor- or ceiling effects (not shown here).

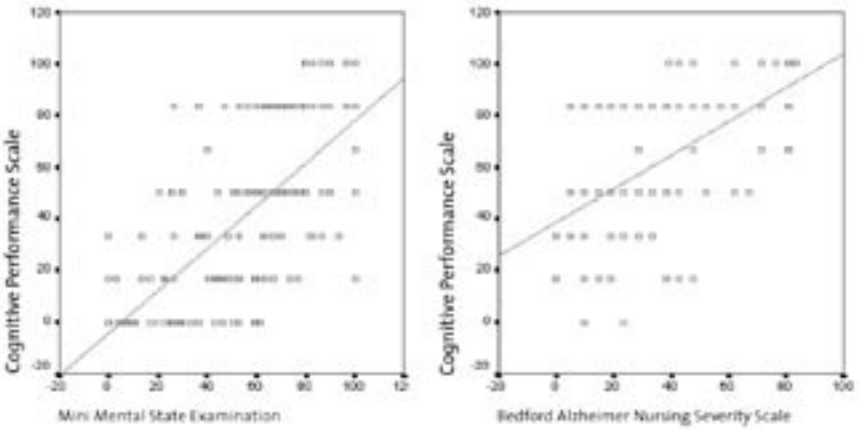
Table 3. Correlations of MDS-scales with comparison measures (Spearman's rho), for total group and for residents of somatic (SOM) and psychogeriatric (PG) units separately

		Total group		SOM residents		PG residents	
		N	rho	N	rho	N	rho
ADL	ADL-SPH x GBI	216	0.77**	110	0.80**	106	0.73**
Cognition	CPS x MMSE	199	0.76**	105	0.66**	94	0.60**
	CPS x BANS-S[1]					106	0.55**
Depression[2]	DRS x GIP-S	211	0.39**	105	0.51**	106	0.34**
	DRS x GDS	72	0.54**	65	0.51**	7	0.79
	DRS x DL	90	0.09	28	0.07	62	0.12

** $p < 0.01$

1 PG residents only
2 In residents with MMSE scores of 15 or higher the GDS was used, and in residents with MMSE scores below 15 the DL was used (see section Instruments)

Figure 1. Scatter diagram of the MDS-Cognitive Performance Scale related to the Mini Mental State Examination (N=199), and to the Bedford Alzheimer Nursing Severity Scale (N=106)



Discussion

In this study, the psychometric properties of MDS scales for ADL, cognition and depression in daily nursing home practice were investigated. The following conclusions can be drawn with regard to the quality of the scales and their use in clinical practice.

First of all, the *ADL-SPH* was found to have very high reliability and validity. Although the high inter-item correlation suggests item-redundancy, shortening the scale is not advised, because the items relate hierarchically to each other. Secondly, the *CPS* has fairly good reliability, but performs somewhat less well in residents of psychogeriatric units. Its validity is good, although the correlation with the MMSE was lower for residents of psychogeriatric units than for residents in somatic units. Compared to the CPS, the MMSE may suffer from a ceiling-effect with regard to measuring cognitive deterioration, which corresponds with its method of assessment: the MMSE is a test of cognition, whereas the CPS is an observational scale. In comparison with the CPS, the BANS-S has a floor-effect. This effect corresponds with the aim of measurement: the BANS-S measures the severity of dementia in people with severe dementia, whereas the CPS measures cognitive disorders in all nursing home residents. The use of the CPS is recommended, because the resident can be monitored for a longer period of time. A further advantage of the CPS over both of the other scales is that the CPS is a hierarchical scale, and can be used to determine several stages of cognitive decline. Thirdly, with the exception of internal consistency, the reliability of the *DRS* is generally somewhat lower than the reliability of the ADL-SPH and the CPS. This is not surprising, because social and psychological aspects of behavior are known to

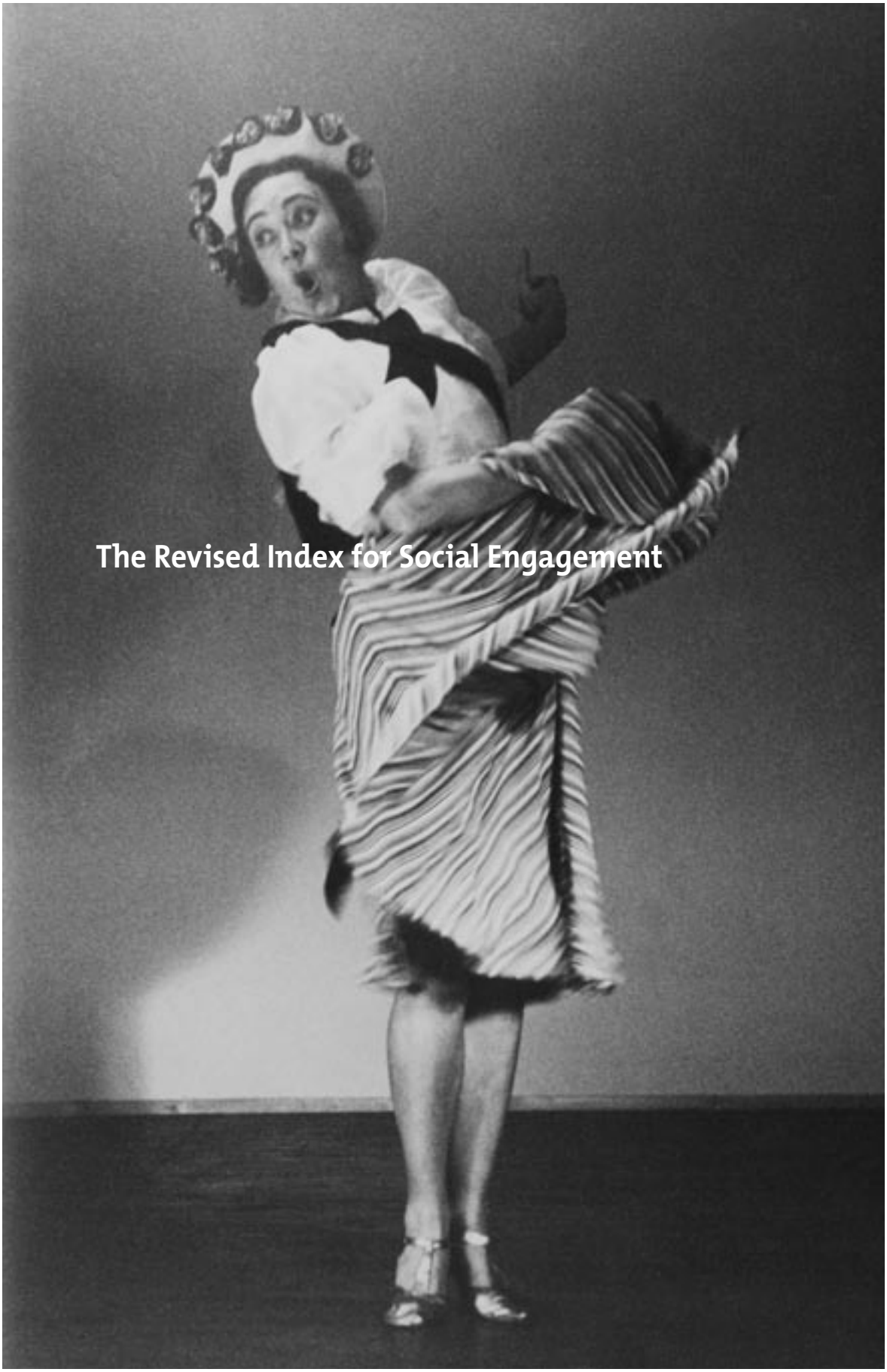
be more difficult to measure than functional aspects. Furthermore, the reliability is lower in residents of psychogeriatric units than in residents from somatic units. The concurrent validity of the DRS in residents with, at the most, moderate cognitive disorders (MMSE ≥ 15) is fair. Thus, in this group of residents it can be used adequately as a measure of depressive behavior. In residents with severe cognitive disorders, however, the results of this study are difficult to interpret. The correlation with the GIP-S is smaller in PG-residents than in SOM-residents, but is still moderate, whereas the correlation with the DL is very weak. This weak correlation is not attributable to the DRS, due to the unknown validity of the DL. A recommendation for future research is therefore to further study the psychometric properties of the DRS and the DL in residents with severe cognitive problems. This research should make use of diagnostic interviews, so that the sensitivity and specificity of these scales can be established. Also the GDS, the GBI and the BANS-S deserve a thorough validation for their use in the Netherlands. Although these scales are often used in clinical practice and have been validated in other countries, this has yet to be done for their use in Dutch nursing homes.

Comparing these results with earlier reports on the properties of the MDS scales, there are important similarities (Morris et al., 1994; Gruber-Baldini et al., 2000; Burrows et al., 2003; Morris et al., 1999), although in general, the results of this study are somewhat less favorable. Nevertheless, in their DRS validity study, Anderson et al. (2003) found a correlation between the GDS and the DRS of .19, whereas in the present study it was .54. The internal consistency of the DRS was also somewhat higher in the present study (.73 as opposed to .68). These differences may be due to different levels of cognitive impairment in the two samples. Possibly, the cognitive impairment of the sample of Anderson et al. was more severe, which might influence both the properties of the DRS and the GDS (Mc Givney et al., 1994). However, this remains uncertain because the level of cognitive impairment in that sample was not reported. The low kappa values of some of the DRS items in the present study were in accordance with results reported earlier for items on mood distress from the corresponding MDS section (Sgadari et al., 1997). We found that the scales, especially the CPS and the DRS, are somewhat less reliable in residents with dementia, which is an important indication for further research.

Some possible limitations of this study should be mentioned. Generalizability may be at stake, because in the Netherlands only a few nursing homes work with the RAI. However, the basic characteristics of the residents (mean age and gender distribution) largely resemble those of the Dutch nursing home population in general (Prismant & Arcares, 2002). Nine of 10 nursing homes working with the RAI at that time participated in the study. Compared to the VURAI-database, there were more women in the sample and the scale-scores were lower. Thus, residents in the sample had better ADL functioning and cognitive functioning

and less depressive behavior (see Table 1). CPS and DRS have a lower reliability in residents of psychogeriatric units, which implies that the sample characteristics may have led to a slight over-estimation of the quality of the scales. On the other hand, under-estimation is also likely. The data were collected in nursing homes with a high shortage of nursing staff at that time, which may have influenced the precision and time-investment in completing the MDS assessments and the various questionnaires. Also, all of the assessors had received training in the MDS protocol, but there might have been variation in their experience in MDS assessment, due to a high staff turnover and the fact that the implementation of the RAI in most of the facilities was still ongoing. The conclusion is that the results will probably not be an over-estimation of the properties of the scales, and possibly even an underestimation.

In conclusion, the MDS scales appear to be useful in daily nursing home practice, and because the scales are observational they can also be used in very severely impaired residents. In addition, observation does not inflict a burden on the residents. The ADL-SPH and the CPS can be used to indicate stages of ADL-dependency and cognitive decline because of their hierarchical nature. When they would be found sensitive to change as well, they could be used to monitor the functioning of a resident over time and to measure the effect of treatment. Therefore, it is strongly recommended to study their responsiveness.



Chapter 4 is submitted as Gerritsen, D. L., Steverink, N., Frijters, D. H. M., Hirdes, J. P., Ooms, M. E., Ribbe, M. W. A Revised Index for Social Engagement for Long-term Care based on RAI/MDS

Chapter 4

The Revised Index for Social Engagement

Social well-being is an important priority for nursing home care. However, notwithstanding the positive connotation of social well-being, most measures of social behavior focus on negative aspects like behavior disturbances. Such behaviors are generally labeled by others as problematic or challenging, making them poor and indirect indicators for social well-being. One scale that may be a useful indicator for social well-being is the Index for Social Engagement (ISE) (Mor et al., 1995), which is derived from the Resident Assessment Instrument/Minimum Data Set (RAI/MDS) (Morris et al., 1990). The ISE highlights the positive features of a resident's social behavior, and it was found to be distinct from conflict relationships, behavior problems and negative affective states (Mor et al., 1995; Kiely, Simon, Jones & Morris, 2000).

Social engagement of the elderly in the community has been defined as the "maintenance of many social connections, and a high level of participation in social activities" (Bassuk, Glass & Berkman, 1999, p. 165). It has also been treated as a synonym of social participation, "representing an active engagement (either actual or symbolic) with the social world and implying that people are choosing to participate" (Bennett, 2002, p. 165). In nursing home settings, Mor et al. (1995) describe social engagement as the "ability to take advantage of opportunities for social interaction and to initiate actions that engage in the life of the home". Kiely et al. (2000) defined it as "the ability to initiate social interaction and be receptive to social overtures from others" (p. 1367). However, when social engagement in the nursing home is formulated in terms of abilities and capacities, the construct depends on the ability to interact, making it difficult to distinguish from physical and cognitive functioning.

Moreover, the validity of the ISE scale itself may be threatened because some of the items are vague and unspecific. ISE items like 'establishes own goals', 'pursues engagement in facility', 'accepts invitations to most group activities', 'at ease doing planned or structured activities' and 'at ease doing self-initiated activities' reflect an indirect measurement approach. They pertain to the opportunity to socially interact, whereas it would be more effective to measure the interaction itself. Moreover, the items 'at ease doing planned or structured activities', 'at ease doing self-initiated activities' and 'establishes own goals' do not have the explicit social orientation that one would expect of the components of a scale that measures social engagement.

This chapter aims to explore opportunities to improve the ISE by addressing the above mentioned considerations.

Methods

Procedure

The first step was to identify the relevant dimensions of social engagement in nursing home residents by means of an expert meeting. These results were used as a basis for determining the scale's content validity. Next, data from Canada and the Netherlands were used to determine whether all items of the Index for Social Engagement (ISE) were needed for it to be an internally consistent scale. Additional data were collected in the Netherlands to assess the inter-rater and intra-rater reliability of the scale and its items. Factor analysis was done with these data to determine whether a single component underlies all items. Construct validity was studied by comparing residents' scores on the ISE with their scores on a scale measuring socially withdrawn behavior and to scales measuring depressive behavior, life satisfaction, cognition and ADL. The scale's suitability for the entire nursing home population was evaluated by stratification of the residents studied into subgroups by their scores on the MDS Cognitive Performance Scale (Morris et al., 1994).

Data collection

In the Netherlands, RAI data were collected in nine nursing homes after the research proposal had been approved by the Medical Ethics Committee of the VU University Medical Center, the participants had been recruited, and written informed consent was obtained from each participant or her representative. Each resident was assessed three times by licensed practical nurses from the facility. First, one nurse completed an MDS assessment and a questionnaire for socially withdrawn behavior (see section 'Instruments'). One to at most four weeks later, the same nurse completed a second MDS assessment to be used to calculate the intra-rater reliability. During those four weeks, a second nurse completed a third MDS assessment to be used to calculate inter-rater reliability. In addition, a psy-

chologist independently administered a self-report scale measuring life satisfaction through an interview of the resident.

The RAI data in Canada came from a pilot implementation of the instrument in nursing homes in Ontario. The RAI was implemented as part of normal clinical practice over approximately a one-year period. Facilities used the RAI assessment as their intake and reassessment instrument on a quarterly basis. All data were anonymized with encrypted identifiers before they were made available to the research team. Ethics clearance was obtained through the University of Waterloo Office of Research. Estimates of the internal consistency of the ISE were based on a sample of 1909 of these residents assessed by trained professionals from the facility.

Measurement instruments

Social behavior measures

The MDS-Index for Social Engagement (ISE) (Mor et al., 1995) is a 6-item observational scale consisting of the following dichotomous items: 'at ease interacting with others', 'at ease doing planned or structured activities', 'at ease doing self-initiated activities', 'establishes own goals', 'pursues involvement in life of facility', and 'accepts invitations to most group activities'. Scores range from 0 to 6 with higher values representing more social engagement. The ISE has been shown to have an internal consistency of .79 in the US (Mor et al., 1995; Kiely et al., 2000) and of .72 in the Netherlands (Achterberg et al., 2003), and an average kappa for inter-rater item reliability of .58 (Mor et al., 1995; Kiely et al., 2000).

The GIP-socially withdrawn behavior (Verstraten & Van Eekelen, 1987; Verstraten, 1988) is a sub-scale of the Behavior Observation Scale for Psychogeriatric Inpatients (GIP). The GIP is an observational scale widely used in nursing homes in the Netherlands that addresses social, cognitive, psychomotor and emotional 'behavioral types' in elderly residents. It was especially developed for cognitively impaired residents, but is also suitable for physically frail residents (Verstraten, 1988). The 8-item GIP-socially withdrawn behavior measures the absence of behavior directed towards others, and/or avoidance of interaction with others. Scores range from 0 to 28, with higher values representing more socially withdrawn behavior. When first published, internal consistency (Cronbach's alpha) of the GIP-Withdrawal was .83, and inter-rater reliability (Pearson's r) was .79 (Verstraten & Van Eekelen, 1987). In a validation study, internal consistency was .84, average inter-rater reliability of the items (Cohen's weighted kappa) was .45, and correlation coefficients to the NOSIE-30 subscales 'Social competence' and 'Social interest' were -.43 and -.81 ($p<0.001$) respectively (De Jonghe, Kat & De Reus, 1994). Internal consistency in this sample was .87.

Well-being measures

The (MDS) Depression Rating Scale (DRS) (Burrows et al, 2000) is an observational scale based on seven MDS-items measuring depressive behavior. Scores range from 0 to 14, with higher values representing a stronger indication for depression. Its internal consistency at development was .75 in the derivation sample, and .71 in the validation sample. Its sensitivity against a psychiatric depression diagnosis was 91% (Burrows et al., 2000). The internal consistency in this sample was .73.

The Philadelphia Geriatric Center Morale Scale (PGCMS) (Lawton, 1975) consists of 17 dichotomous items measuring life satisfaction. It is a self-report scale ranging from 0 to 17, with three categories: sense of satisfaction with self, a place in the world for self, and acceptance of what cannot be changed. It has been regularly used in Quality of Life and well-being research (e.g. Faulk, 1988; Yamashita, Iijima, & Kobayashi, 1999). Internal consistency in this sample was .76.

Functioning measures

The (MDS) Cognitive Performance Scale (MDS-CPS) (Morris et al., 1994) is a 7-point hierarchical observational scale that rates cognitive impairment from 0 (intact) to 6 (very severe impairment). Its reported internal consistency ranges from .70 to .88 (Gruber-Baldini et al., 2000; Morris et al. 1994). Its sensitivity and specificity against the MMSE were .94 (Hartmaier et al., 1995) and its correlation with the MMSE has been estimated at -.65 (Gruber-Baldini et al., 2000). Snowden et al. (1999) found that the CPS had a larger effect size than the MMSE. The internal consistency in this sample was .74.

The (MDS) ADL Self-Performance Hierarchy (ADL-SPH) (Morris et al., 1999) is an observational scale for measuring ADL-dependence. It measures resident self-involvement in personal activities of daily life and ranges from 0 (independent) to 6 (total dependence). Reported psychometric properties at introduction were kappa-values ranging from .87 to .94, and an alpha of .90 (Morris et al., 1999). Internal consistency in this sample was .84.

Analyses

CONTENT VALIDITY: A literature search on (sub-) scales measuring positive social behavior was conducted in September 1999. 'Social engagement' did not yield any instruments other than the ISE, so the search was extended to instruments measuring 'positive social behavior' yielding 13 additional scales (see results section for details). The items of the instruments identified in this search were categorized into different dimensions of social behavior for nursing home residents (see Table 1). An expert meeting was convened with ten physicians and ten psychologists who were specialists in this population. Participants were asked to rate the different dimensions of social behavior with respect to

their relevance for residents with and without dementia, by appointing a grade between 0 and 10 to each dimension. The ISE was then studied to determine the presence of the dimensions that were considered to be most relevant by the experts. The relevance of dimensions that were not represented in the ISE was compared with the relevance of the dimensions included in the ISE using paired t-tests. Highly relevant dimensions that were not represented in the ISE or in the MDS were measured with new items that were added to the data collection in the Netherlands.

RELIABILITY: Internal consistency of the ISE was established using Cronbach's alpha. The inter-rater and intra-rater reliability of the ISE items were determined by calculating Cohen's kappa (Cohen, 1960; Landis & Koch, 1975) over the entire group and stratified by cognitive functioning. The inter-rater and intra-rater reliability of the scale were examined with the intraclass correlation coefficient (Shrout & Fleiss, 1979). Principal component analysis was done to establish whether the scale's items load on one factor, and principal axis factoring with varimax rotation provided insight into what dimensions were represented in the index.

CONSTRUCT VALIDITY: As no other positive measure of social engagement was available discriminant validity was studied, instead of convergent validity, by determining the extent to which the ISE correlates negatively with a scale measuring socially withdrawn behavior. To study the validity of the 'social engagement' construct as an indicator for social well-being and as distinct from measures of functioning, the extent to which the ISE correlates with depressive behavior, life-satisfaction, cognition and ADL was studied.

Results

Sample description

At least one MDS-assessment was done for 227 of the 237 Dutch residents for whom informed consent was obtained and 199 included the ISE-items (section F1). Repeated assessments by the same rater and dual assessments by a second rater were available for 142 and 151 residents, respectively. Of the 199 residents, 77% were female (N=154), and 52% (N=103) suffered from moderate to severe cognitive problems (CPS-score > 2).

Content validity

The literature search on positive social behavior resulted in the identification of 15 measurement (sub-) scales that deal with positive social behavior in nursing home residents (including the ISE), of which 14 could be retrieved (Baum, Edwards, & Morrow-Howell, 1993; Duine, 1991; Farina, Arenberg, & Guskin, 1957; Gorissen, 1986; Harvey et al., 1997; Helmes, Csapo, & Short, 1987; Honigfeld, Gillis & Klett, 1966; Jette et al., 1986; Liseno & Kennedy, 1975; Mor et al., 1995; Peavy et al.,

1996; Saxton et al., 1990; Spiegel et al., 1991; Verstraten, 1988). With the exception of one (Farina, Arenberg & Guskin, 1957), the instruments were observational and developed for a population of chronically ill elderly patients. Some examples of the aims of these instruments are measurement of 'social contact' (Duine, 1991); 'interpersonal behavior' (Farina, Arenberg & Guskin, 1957); and 'social competence' (Gorissen, 1986). Table 1 shows the dimensional structure of the identified social behavior instruments. Three components could be found: a) items about the cognitive ability to make contact; b) items about the presence and quality of social interaction; and c) items about participation in activities.

The participants in the expert meeting (n=20) rated the relevance of the dimensions for residents with and without dementia as shown in Table 1. The dimensions 'actively making contact' (mean: 8.0; confidence limits of the mean (clm): 7.4-8.6) and 'reacting to others' (mean 8.0; clm: 7.4-8.6) were considered to be the most important by the clinical experts. 'Initiation of activities' (mean 6.5; clm: 6.0-7.0) was considered least important. However, it should also be noted that there were relatively few statistically significant differences in the ratings of the various dimensions of social behavior since most grades of relevance had overlapping confidence intervals.

In Table 1, the dimensions that are represented in the Index for Social Engagement are made bold. Each ISE item was placed in the dimension that contained those items of the other instruments that correspond best to the ISE item. Paired t-tests of these dimensions with the dimensions that were not represented in the ISE showed that the 'ISE-dimensions' were appointed a lower average grade of relevance than the dimensions 'reacting to others' (p-values of .008; .018; .002; .008 respectively), and 'actively making contact' (p-values of .010; .022; .004; .005 respectively). With regard to the dimension 'conversational skills', only the difference with the grade for 'initiation of activities' was significant at the 0.05 level. The dimension 'social relationships' was not considered as more important than the ISE-dimensions. The high expert ratings for relevance of the two dimensions 'actively making contact' and 'reacting to others' in the nursing home population provided evidence that it would be useful to add items representing these dimensions to the ISE. Two new items were formulated. The items are 'initiates interaction(s) with others' and 'reacts positively to interactions initiated by others'. These items were also collected as part of the inter-rater and intra-rater reliability testing.

One ISE-item appeared not to be categorizable: item F1d 'establishes own goals' was not represented in the social dimensions considered here. One might argue that this item could be dropped because it is not a conceptually explicit measure of social orientation.

Table 1. Dimensional structure and means, (SD), and 95% confidence intervals of appointed grades of relevance for all residents and for residents with and without dementia separately

Positive social behavior dimensional structure		Grades of relevance		
Dimension	Sub-categories	Residents no dementia	Residents with dementia	All residents
Cognitive abilities				
Conversational skills	*Expressional skills*	8.25 (1.5)	7.2 (2.1)	7.7 (1.6)
	Understanding others	7.6-8.9	6.2-8.1	7.0-8.5
(Quality of) interaction				
Actively making contact	*Initiating contact*	8.2 (1.1)	7.8 (1.5)	8.0 (1.2)
	Sustaining interaction	7.7-8.8	7.1-8.5	7.4-8.6
	Talks about self			
	Offering help			
	Asking for help			
Reacting to others	*Reacting to others*	8.2 (1.1)	7.8 (1.4)	8.0 (1.2)
	Making eye-contact	7.6-8.7	7.2-8.4	7.4-8.6
	Happy with visits			
	Shows recognition			
Attitude in interaction[1]	*Friendly towards others*	7.6 (1.3)	6.8 (1.4)	7.2 (1.3)
	Assertive in group	7.0-8.2	6.1-7.5	6.6-7.8
	Involved with, interested in others			
Social relationships	*Friendship*	7.4 (1.3)	6.2 (1.7)	6.8 (1.4)
	Carry on contacts	6.8-8.0	5.4-7.0	6.2-7.4
Activities				
Experience of activities[2]	*Enjoying activities*	7.0 (1.5)	6.7 (1.5)	6.8 (1.5)
	Carries on when frustrated	6.3-7.7	6.0-7.4	6.1-7.5
initiation of activities[3]	*Spontaneous activities, occupations*	6.7 (1.2)	6.2 (1.2)	6.5 (1.1)
	Spontaneous activities with others	6.2-7.3	5.7-6.8	6.0-7.0
	Joins organized activities			
Interest in environment[4]	*Interested in what's going on*	7.7 (1.1)	6.8 (1.7)	7.2 (1.2)
	Interested in world outside nursing home	7.1-8.2	6.0-7.6	6.6-7.8

Representation of ISE items in dimensional structure: **1** F1a (At ease interacting with others); **2** F1b (At ease doing planned or structured activities); **3** F1c (At ease doing self-initiated activities) & F1f (Accepts invitations to most group activities); **4** F1e (Pursues involvement in the life of facility)

Reliability

Internal consistency

In the total resident sample in Canada, the alpha of the ISE was .82 (Table 2). When categorized by CPS-score, the internal consistency appeared to drop among those with more severe cognitive problems.

This drop in alpha scores by CPS was most pronounced when items F1a, F1b or F1f were excluded from the ISE, which suggests they are important items to keep in the scale. Table 2 also shows that excluding item F1d had the least impact on the ISE. Indeed, that change slightly improved the alpha in some CPS-groups (compare columns of 'total ISE' and 'without F1d'). Similarly, item F1c did not appear to have a very important impact on the scale.

Table 2. Internal consistency (alpha) of ISE and alpha if one of the items would be deleted, by CPS-score, on Canadian and Dutch data

Country	CPS Group[1]	N	Total ISE	Without F1a	Without F1b	Without F1c	Without F1d	Without F1e	Without F1f
Canada	All	1909	0.82	0.80	0.77	0.79	0.81	0.79	0.79
	CPS 0	309	0.82	0.82	0.77	0.79	0.81	0.78	0.78
	CPS 1	240	0.77	0.75	0.69	0.73	0.78	0.73	0.74
	CPS 2	131	0.73	0.71	0.66	0.70	0.73	0.67	0.66
	CPS 3	437	0.70	0.65	0.59	0.69	0.71	0.65	0.63
	CPS 4	105	0.65	0.63	0.53	0.63	0.63	0.61	0.60
	CPS 5	372	0.66	0.54	0.53	0.66	0.67	0.65	0.54
Netherlands	All	199	0.68	0.65	0.61	0.63	0.68	0.61	0.67
	CPS ≤ 2	96	0.65	0.66	0.57	0.58	0.65	0.55	0.62
	CPS > 2	103	0.53	0.38	0.34	0.53	0.61	0.49	0.44

1 due to missing data, calculation in CPS 6 was not possible

The internal consistency was lower in the Netherlands. For example, the alpha for the total group was .68. However, the differences across CPS groups and the behavior of individual items were similar to what was found in the Canadian sample. The drop in alpha was especially striking when items F1a, F1b or F1f were excluded. On the other hand, excluding item F1d even led to an increase of alpha in the low cognition group from 0.53 to 0.61. Excluding item F1c had no effect in the low cognition group, but did lower alpha values for the high cognition group. Hence, these analyses of content validity and internal consistency indicated that it was necessary to drop item F1d, and that it was reasonable to drop F1c from the original ISE.

Intra- and Inter-rater Reliability

The inclusion of the two new items identified in the expert meeting as part of a revised version of the ISE was examined only in the Dutch study. Table 3 gives the reliability properties of the original ISE and of a revised ISE without F1c and F1d but with the two newly formulated items (RISE). The numbers of cases for the ISE and the RISE differ, because the answers on the newly formulated items were not collected for all residents.

Table 3. Internal consistency (alpha) and intra- and inter-rater reliability of items (Kappa) and scales (ICC) of ISE and RISE, for total group and for residents with limited cognitive impairment (CPS ≤ 2) and with serious cognitive impairment (CPS > 2) separately

	ISE 6 items	N	RISE drop F1c&F1d, add 2 new items	N
Crohnbach's alpha (miic)[1]				
Total group	.68 (.27)	199	.73 (.31)	189
CPS ≤ 2	.65 (.23)	96	.67 (.25)	91
CPS > 2	.53 (.12)	103	.70 (.27)	98
Intra-rater Kappa, means of items (range)				
Total group	.60 (.54-.67)	130	.60 (.49-.78)	132
CPS ≤ 2	.54 (.43-.59)	68	.50 (.23-.72)	68
CPS > 2	.61 (.47-.81)	62	.64 (.47-.81)	62
Intra-rater ICC of scale (confidence interval)[2]				
Total group	.75 (.67 – .82)	130	.76 (.67 – .83)	119
CPS ≤ 2	.72 (.58 – .82)	68	.68 (.52 – .79)	62
CPS > 2	.68 (.52 – .80)	62	.76 (.63 – .85)	57
Inter-rater Kappa, mean of items (range)				
Total group	.49 (.38-.61)	137	.54 (.38-.65)	137
CPS ≤ 2	.45 (.33-.62)	69	.45 (.21-.72)	69
CPS > 2	.38 (.14-.61)	68	.54 (.35-.79)	68
Inter-rater ICC of scale (confidence interval)				
Total group	.64 (.53 – 73)	137	.75 (.66 – .82)	130
CPS ≤ 2	.53 (.33 – .68)	69	.64 (.46 – .76)	64
CPS >	.65 (.49 – .77)	68	.78 (.66 – .86)	66

1 miic = mean inter item correlation, 2 CI = 95% confidence interval

The internal consistency of the RISE increased considerably compared with the ISE, especially in the low cognition group (CPS>2)(.70 and .53 respectively). By way of comparison, the internal consistency of an ISE without F1c and F1d was .66 in the total group, .63 in residents with CPSFFI2 and .64 in residents with CPS>2, which would only be an improvement for the low cognition group, and a slight decrease in the other groups. Intra-rater reliability estimates stayed about the same. The clearest improvement was found in the inter-rater characteristics of the RISE. Mean inter-rater kappa of the items increased from .49 to .54 in the total group and from .38 to .54 in the low cognition group. The inter-rater ICC of the scale improved from .64 to .75 in the total group, and in both subgroups with more than one decimal point (from .53 to .64 and from .65 to .78, respectively).

Factor structure

FACTOR STRUCTURE OF ISE: Principal component analyses with extraction of one factor showed one factor with an eigenvalue of 2.4 on which all 6 items of the scale loaded above .40, with the lowest being .53 (item F1f) and the highest .72 (item F1b), explaining 39% of the variance (N=199, see Table 4). Table 4 shows the factor solution after Principal Axis Factoring with varimax rotation extracting factors with an eigenvalue above 1, which showed a second factor on which the items that were dropped for the RISE, F1c and F1d, loaded with an eigenvalue of 1.3. The total variance explained was 60%.

FACTOR STRUCTURE OF RISE: Principal component analyses with extraction of one factor showed one factor with an eigenvalue of 2.6 on which all 6 items of the new scale loaded, with the lowest being .61 (item F1e), and the highest .71 (Xtra01, a new item), explaining 43% of the variance (N=189). Principal Axis Factoring with varimax rotation extracting factors with an eigenvalue above 1 showed another factor with an eigenvalue of 1.1, on which the two new items loaded, and also item F1a, which loaded almost equally on both factors (see Table 4). The total variance explained was 66%.

Table 4. Factor structure of ISE and RISE

		ISE (N=199)			RISE (N=189)		
		PCA[1]	PAF[2] varimax rotation		PCA	PAF varimax rotation	
Item		First Factor	Factor 1	Factor 2	First Factor	Factor 1	Factor 2
F1a	At ease interacting with others	**.59**	.38	.25	**.66**	.40	.37
F1b	At ease doing planned or structured activities	**.72**	.73	.15	**.65**	.77	~ 0
F1c	At ease doing self-initiated activities	**.67**	.29	.59			
F1d	Establishes own goals	**.51**	~0	.84			
F1e	Pursues involvement in the life of facility	**.71**	.52	.31	**.61**	.51	.18
F1f	Accepts invitations to most group activities	**.53**	.61	~0	**.66**	.50	.26
Xtra1	Initiates interaction(s) with others				**.71**	.28	.67
Xtra2	Reacts positively to interactions initiated by others				**.62**	.11	.75

1 Principal component2 PAF: Principal Axis Factoring

Construct validity

Table 5 shows the correlation coefficients for the ISE and the RISE with socially withdrawn behavior (for discriminant validity), and with depressive behavior, life satisfaction, cognition and ADL. Although ISE and RISE were highly correlated (rho=.90), there were some differences in their correlation to other measures. The RISE had a somewhat stronger negative correlation to socially withdrawn behavior, especially in the low cognition group (CPS>2). The scales' correlations with depressive behavior and life satisfaction were about the same. Both scales were significantly correlated to cognition, but the correlation coefficients for the RISE were lower, a difference most prominent in the high cognition group. The correlation to ADL was about the same, although in the low cognition group, the correlation coefficient for the RISE was somewhat higher.

Table 5. Correlations (Spearman's rho) of ISE and RISE with socially withdrawn behavior, cognition, and depressive behavior for the total group (N=188), and for residents with limited cognitive impairment (CPS ≤ 2; N=91) and with serious cognitive impairment (CPS > 2; N=97) separately

Scales	ISE			RISE		
	Total	CPS≤2	CPS>2	total	CPS≤2	CPS>2
RISE	.90**	.87**	.89**			
Socially withdrawn behavior	-.63**	-.60**	-.48**	-.67**	-.59**	-.62**
Depressive behavior	-.32**	-.20	-.44**	-.31**	-.17	-.42**
Life satisfaction[1]	-.01	.13	-.18	.035	.11	-.05
Cognitive impairment	-.53**	-.38**	-.28**	-.45**	-.29**	-.26*
ADL-dependency	-.31**	-.13	-.22*	-.32**	-.12	-.29**

1 Only 67 participants were able to answer all questions of the PGCMS. Of these, 43 had a CPS of 2 or lower, 24 had a CPS higher than 2.

* $p < 0.05$, ** $p < 0.01$

Discussion

This chapter examined the construct of social engagement and the psychometric properties of the Index for Social Engagement, and it proposes a new version of the scale: the Revised Index for Social Engagement (RISE). Two ISE-items were dropped and two new items were added to create the RISE. Compared with the original ISE, the RISE has higher content validity, higher internal consistency, and better inter-rater reliability. This improvement is most pronounced in residents with severe cognitive problems. The discriminant validity of the RISE (and ISE) appears to be good. The construct validity of the RISE is better than the ISE with regard to its independence from cognition, and the two scales are about the same in relation to ADL. With respect to the broader issue of social well-being, neither the ISE nor the RISE were strongly associated with 'self reported life satisfaction', an independent measure of general well-being, but they both do relate to the observational measure for depressive behavior.

As mentioned in the introduction, the scale's dependence on 'abilities' may be an important issue for debate. Although the participants in the expert meeting rated cognitive abilities (conversational skills) as being relatively important, one might argue that including them in a scale measuring social engagement would threaten the construct's distinctness in this population. Rather, cognition and communication abilities should be considered to be *determinants* of social engagement, not components of the construct. Social engagement should not be defined in terms of abilities, but in terms of the orientation towards participating in one's social environment, and the RISE is a useful operational measure of 'participating in social interaction and activities'.

Another question pertains to the indirect approach of operationalizing social engagement as participating in activities. Although the dimensions on

activities were considered to be the least important by the experts, items of this type were present in most scales. Perhaps this is because participation in activities can be observed with relative ease and a good level of accuracy. Also, stimulating and engaging residents by offering them recreational therapy and organizing activities is an important focus of daily care, especially in residents with (severe) dementia. Therefore, it is reasonable to include this highly significant clinical intervention as part of the ISE.

It was also noted earlier that three of the six initial ISE items do not have an explicit social orientation. One of these, 'establishes own goals', was not in the dimensional structure (see Table 1) and, like the second item 'at ease doing self-initiated activities', it was not important for the internal consistency of the scale. Both items reflect 'autonomy' (Mor et al., 1995), and indeed they loaded together on a second factor. The third item 'at ease doing planned or structured activities' did prove to be important for the scale. The description in the RAI Manual (Morris, Murphy & Nonemaker, 1995) emphasizes a social orientation (as opposed to the aforementioned items), which may explain why this item was important for the scale. The item does not exclude solitary activities, which may introduce some measurement error; however, adding an explicit social orientation may lead to assessors excluding (group) activities whose central purpose may not be socializing but includes interaction with others. This would constitute another type of measurement error. Therefore, this item should remain in its original form, without adding an explicit social orientation.

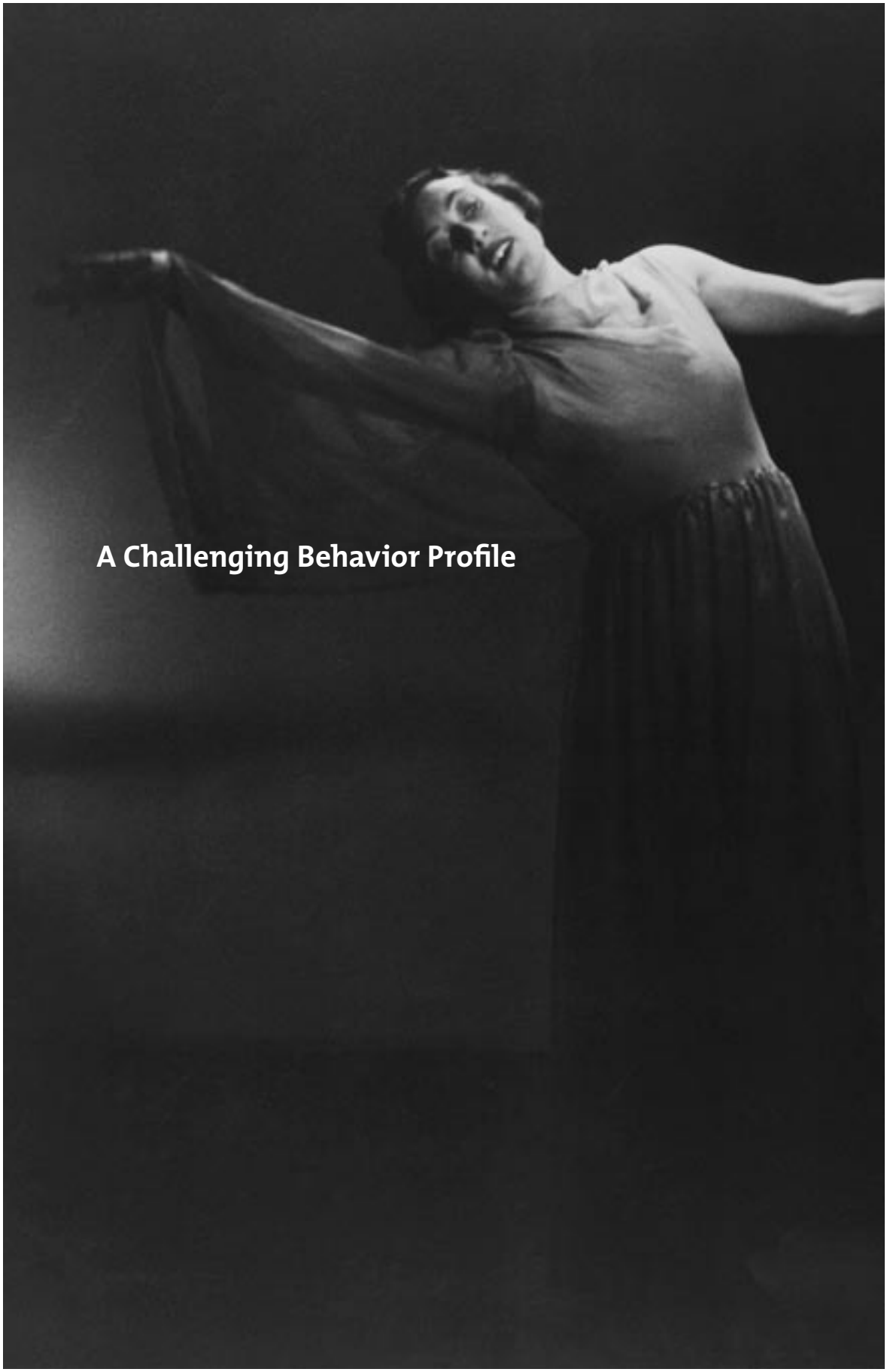
The present method of reviewing the ISE by examining content validity – a step usually taken in scale-development (Streiner & Norman, 1995) – enabled the exploration of the construct of positive social behavior from a perspective of clinical relevance. This led to the revision of the ISE and to the inclusion of two new items that represent the component '(Quality of) interaction'. The factor structure of the RISE was found to reflect the construct's components 'activities' and 'interaction'. The new items not only added to the scale's content validity and thus to the representation of the construct of social engagement in the index, but also appear to enhance the scale's psychometric quality.

The two new RISE items that appear promising in the Netherlands need to prove their value in other countries. It will be possible to determine their quality in the near future, since they will be included in the new inter*RAI* Long-Term Care assessment instrument. An issue with one of the items came to light when translating the items into English, providing a possible explanation for its relatively low kappa values. The item 'reacts positively to interaction initiated by others' had a more neutral formulation in Dutch. For assessors of this item, it may have been unclear how to code *negative* reactions to initiatives.

Further study is necessary to explain why the internal consistency and inter-rater item reliability of the ISE was significantly worse in the Netherlands (Achterberg et al., 2003 & this study) than in Canada and the United States. This may be because the assessment in the Netherlands was done by licensed practical nurses who provide daily care, whereas in other countries assessments were generally done by more highly qualified or specially trained research nursing staff. Another possibility is that in most Dutch nursing homes, the level of familiarity with the RAI is still not optimal because its implementation is still ongoing. Both of these issues point to the importance of effective, on-going educational programs to support staff in producing high quality data.

Finally, the new RISE scale's construct validity should be further tested with regard to the question whether the scale is a good indicator of (social) well-being. Although the scale was negatively correlated to depressive behavior, it was not associated to a self-report life satisfaction scale (PGCMS). On the other hand, Gilbart and Hirdes (2000) found a strong relationship between the ISE and three different observational measures of psychological well-being. The indeterminate findings of the present study might be explained by the use of a self-report measure for psychological well-being in combination with an observational measure for social engagement. The negative (not significant) correlation of ISE and RISE with PGCMS in residents with a CPS-score above 2 may also have been the result of an inability to measure life satisfaction reliably. The use of self-report and observational measures and their comparability, especially in people with severe cognitive problems, is an important area for further research.

In conclusion, the Revised Index for Social Engagement deserves a place in the suite of clinical scales like the ADL-SPH, CPS, DRS, and CHESS (Hirdes et al., 2003), developed for and embedded in the Resident Assesment Instrument for Long-Term Care. These scales can be used to monitor, evaluate and improve care.



A Challenging Behavior Profile

Chapter 5 is submitted as Gerritsen, D. L., Achterberg, W. A., Steverink, N., Ooms, M. E., Frijters, D. H. M., & Ribbe, M. W. The MDS-Challenging Behavior Profile: an innovative approach for nursing home care

Chapter 5

A Challenging Behavior Profile

In the last fifteen years, various instruments have been developed for measuring so-called 'inappropriate' behavior of nursing home residents (mostly with dementia). This behavior goes under various names, like *agitated behavior* (Cohen-Mansfield & Billig, 1986; Sinha et al., 1992; Finkel, Lyons, & Anderson, 1993; Bliwise & Lee, 1993; Rosen et al., 1994), *problem behavior* (Ray, Taylor, Lichtenstein & Meador, 1992), *obstreperous behavior* (Drachman, Swearer, O'Donnell, Mitchell, & Maloon, 1992), *behavior disturbances* (Gauthier, Baumgarten, & Becker, 1996); *dysfuntional behavior* (Molloy, Bédard, Guyatt, & Lever, 1996), *behavioral pathology* (Reisberg, Auer, & Monteiro, 1996), *disruptive behavior* (Beck et al., 1998), and *challenging behavior* (Allen-burge, Stevens en Burgio, 1999; Mahoney, Volicer & Hurley, 1999). The behavior in question is often negatively labeled, but it is not certain why and for whom it is negative. Moreover, most of the approaches that are used in research do not accurately differentiate between the behavior itself, its implications for the resident, and the possible causes of the behavior. Therefore, it is difficult to both understand and intervene in this behavior.

Several approaches and measures, among which is the 'Behavioral and Psychological Symptoms in Dementia' approach (Finkel, 2002; Lawlor, 2002), partly move away from the behavior itself ('behavioral') and mix it with indicators of its causes ('psychological'). This is puzzling, because, typically, every psychological symptom will have its behavioral expression. For example, delusions are an obvious psychological symptom when a resident repeatedly expresses that people are following her. Apparently, when the behavior is clearly related to a psychological cause or syndrome (in this case, delusions), some approaches move away from the behavior itself and formulate items at the psychological symptom level (e.g.

DBRI: Molloy et al., 1996; BEAM-D: Sinha et al., 1992; COBRA: Drachman et al., 1992: BEHAVE-AD: Reisberg et al., 1996).

In addition, various approaches aim to exclude 'cognitive disturbances' from behavioral scales (e.g. Reisberg et al., 1996; Auer et al., 1996; Tariot et al., 1995; Lawlor, 2002). Cognitive disorders may cause typical behavior, for instance putting things into places where they don't belong. When the behavior is directly attributable to cognitive deterioration, it is often not included in a measure of challenging behavior, irrespective of its 'inappropriateness'.

In nursing home care, 'behavior' can be the expression of various syndromes and symptoms. Most residents are very impaired and have a lot of co-morbidity, making the precise cause of the behavior often far from clear. Therefore, it is difficult to employ 'the' cause of behavior in measurement and intervention strategies. Understanding, measuring and intervening in challenging behavior may benefit more from an approach in which the factual behavior and its possible implications for the resident are considered, because these give practical clues for intervention.

Insight in the implications of challenging behavior can be obtained by starting from the perspective that resident behavior takes place in a social context, and that social interaction has to do with the fulfillment of needs. This perspective is taken by, among others, the Social Production Functions (SPF) theory (Lindenberg, 1996; Steverink et al., 1998; see Chapter 2). Following the SPF theory, challenging behavior can be linked to, and is foremost about, the well-being of the resident. It threatens the achievement of well-being needs, although the behavior may *in itself* not be problematic for the resident. One of the theory's basic views clarifies the magnitude of challenging behavior. It describes that every individual is aimed at fulfillment of well-being goals (i.e. needs), and for that uses resources (i.e. 'things' that she has and does to achieve well-being, for instance food, health care, money, a spouse, but also cognitive and ADL functioning, or social activities). Every individual is, to some degree, dependent on others to achieve well-being, but in nursing home residents, this dependence may be much stronger. Whereas for social well-being, every individual's social goals need to be fulfilled by others, the resources of a resident decrease so strongly that she has very limited possibilities to fulfill her goals, even very basic goals, and needs others to help her with that. Given this extreme dependence on others for (social) well-being, if the resident's behavior evokes irritation, frustration and/or rejection, and the willingness of people surrounding the resident to fulfill her well-being goals or resources is challenged, this *challenging behavior* is a huge threat to the resident's well-being.

In this chapter, it is aimed to develop a screening instrument for challenging behavior and investigate its validity using the views of the SPF theory. This implies that it should measure behavior, irrespective of its possible causes, that

may cause others to be reluctant to meet the resident's well-being goals. Next to an internally consistent overall scale, the possibility of developing sub-scales is studied, which would provide a behavioral profile with information about what type of challenging behavior is expressed by the resident. This would give clues for subsequent intervention. The MDS of the Resident Assessment Instrument (RAI) is an obvious item source, as it is used in daily nursing care in many long term care facilities and its behavioral items have good reliability and validity (Morris et al., 1990, Hawes et al., 1995; Frederikson et al., 1996; Snowden et al., 1999; Snowden, Sato & Roy-Byrne, 2003).

This chapter is divided in two parts. In the section Scale design a scale is constructed based on a sample of nursing home residents. In the section Validity, the validity of the resulting scale is determined on a second sample.

Scale design

Methods

Five clinical experts independently selected MDS-items to fit the challenging behavior approach as suggested in the introduction. This means that they selected items on resident behavior that may evoke reactions such as irritation, frustration and/or rejection by (nursing) staff, other residents and/or visitors, which would undermine their willingness to fulfill the resident's needs. Only items that were selected by at least 2 of the experts were included in the next step. Next, frequency distributions of these items were studied in a group of nursing home patients with Alzheimer's disease, a group with other dementias, a group without dementia, and in the total group. If an item was scored with a very low frequency in one or more of these groups (below 10%), it was considered to be non-discriminative, and was therefore discarded. Subsequently, an MDS-dataset was used for analysis of internal consistency and for exploratory factor analysis, to study the possibility of developing subscales for 'behavioral dimensions'. The dataset on which the challenging behavior scale was constructed consisted of a MDS 2.0 assessment for all 656 residents of three nursing homes in the Netherlands, assessed between September 2002 and April 2003. The mean age was 81. Of these, 74% were women, and 71% suffered from moderate to severe cognitive problems (CPS-score > 2).

Results

Step 1. The MDS items that were selected by two or more of the experts were: periods of restlessness (B5d); negative statements (E1a); repetitive questions (E1b); repetitive verbalizations (E1c); repetitive persistent anger with self or others (E1d); recurrent statements that something terrible is about to happen (E1g); repetitive health complaints (E1h); repetitive anxious complaints/concerns

(E1i); repetitive physical movements (E1n); withdrawal from activities of interest (E1o); reduced social interaction (E1p); wandering (E4aa); verbally abusive behaviors (E4ba); physically abusive behaviors (E4ca); resists care (E4ea); covert/open conflict with or repeated criticism of staff (F2a); unhappy with roommate (F2b); unhappy with residents other than roommate (F2c); and openly expresses conflict/anger with family/friends (F2d).

Step 2. The following items were scored with a frequency below 10% and therefore excluded: E1g, F2b, F2c & F2d.

Step 3. The results of the internal consistency analysis and factor analysis are presented in Table 1. Cronbach's alpha (Cronbach, 1951) of the 15 items was .81, and all items contributed sufficiently to the scale. Principal component analysis revealed one component that explained 28% of the variance, and three additional components that had an eigenvalue above 1. Together, these explained an additional 32% of the variance (60% total variance explained by 4 components). Principal component analyses with these four factors and varimax rotation revealed four sub-scales with meaningful content. They were named Conflict, Withdrawal, Restlessness and Repetition, and Claiming. One item, item E1d (repetitive persistent anger with self or others), loaded considerably on two factors (see Table 1). Although item E1o and E4aa loaded below .40 on the first component (.39, .34, & .35 respectively), after varimax rotation they appeared important for 'their' factor. Subsequent internal consistency analyses of the sub-scales revealed alphas ranging from .67 to .80.

The items of two of the sub-scales have different response categories. To calculate sub-scale-scores the items from section E4 were recoded (four response categories on frequency of occurrence). The second and third category of these were recoded into one category, so that they correspond better with the E1 items (which have three response categories on frequency of occurrence). Item B5d (3 response categories concerning presence and onset) was recoded into present/absent. Just as for item F2a, the presence of behavior results now in a score of 1. This means that on the E-items a resident can attain a higher score than on B5 and F2a.

After recoding, the 5-item sub-scale Conflict had a range of 0-9; the 2-item Withdrawal a range of 0-4; the 3-item Restless & Repetitive a range of 0-5; and the 5-item Claiming a range of 0-10. All sub-scales were very positively skewed. The medians of the Conflict and Withdrawal sub-scales were 0, the medians of the Restless & Repetitive and Claiming sub-scales 1. The corresponding means were 1.2, .90, 1.2 and 1.8, respectively.

Although the sub-scales will have the most clinical relevance when they are calculated separately and considered as a behavioral profile, the scores can

Table 1. Internal consistency (alpha) and factor structure of challenging behavior (sub-)scales (N=656)

Dimension	Item		Alpha	Factor Structure				
				PCA[1]	PCA with varimax rotation			
Conflict	E1d	Repetitive persistent anger with self or others	**.68**	.72	.47	.59	.14	.10
	E4ba	Verbally abusive behaviors		.66	.25	.65	.32	~0
	E4ca	Physically abusive behaviors		.45	~0	.67	.37	-.14
	E4ea	Resists care		.46	~0	.68	.12	.19
	F2a	Conflict with or repeated criticism of staff		.42	.21	.58	-.19	.18
Withdrawal	E1o	Withdrawal from activities of interest	**.80**	.39	~0	~0	.13	.88
	E1p	Reduced social interaction		.40	~0	.12	.21	.86
R & R[2]	B5d	Periods of restlessness	**.67**	.59	.29	.13	.64	.11
	E1n	Repetitive physical movements		.53	.11	~0	.79	.18
	E4aa	Wandering		.35	-.10	.15	.64	.13
Claiming	E1a	Negative statements	**.76**	.65	.62	.43	~0	.16
	E1b	Repetitive questions		.61	.71	~0	.34	~0
	E1c	Repetitive verbalizations		.61	.60	.11	.40	~0
	E1h	Repetitive health complaints		.43	.70	~0	-.14	~0
	E1i	Repetitive anxious complaints/concerns		.57	.78	~0	~0	~0
Overall			**.81**					

1 Principal Component Analyses, 2 Restlessness & repetition

also be summated because the items form one overall (principal) component and an internally consistent overall scale. The total score can be used as a basic indicator of the presence of challenging behavior. The sub-scales have different ranges, and as a consequence, they contribute with varying strength to the overall scale. However, given the focus of the overall scale, i.e. screening for the presence of challenging behavior, it was decided to simply summate the residents' scores on all 15 items. On this challenging behavior scale, which had a range of 0 to 22

in the present sample (with a theoretical maximum of 28), 82% of all residents had a score above zero, 50% had a score of 4 or higher, and 25% had a score of 8 or higher.

Validity

A second, independent, dataset was used to study reliability and validity of the challenging behavior scale and its sub-scales. Dual assessments enabled the calculation of inter-rater reliability of the items and the scales. Validity was studied by determining the (sub-) scales' correlation with each other (hypothesis 1) and with other behavioral scales of the same concepts (hypothesis 2), and by determining whether the scale and its sub-scales correlated as expected with cognition (hypothesis 3). Lastly, the feasibility of our approach was studied (hypothesis 4), by studying whether the scales indeed correlated to social well-being as indicated by social engagement. The following hypotheses were formulated:

1) The four new sub-scales are significantly positively correlated with each other, as they are part of the same construct, but not highly correlated, as they do not measure the same dimension of the construct.
2) Each new sub-scale is coupled with a corresponding measure, each of which is a sub-scale of the Behavior Observation Scale for Psychogeriatric Inpatients. The correlations of these two will be higher than the correlations of each of these scales to the other (sub-) scales.
3) As challenging behavior increases with greater cognitive impairment (Beck et al., 1998), a positive relationship must exist between the (sub-) scales and cognitive deterioration as measured by the MDS-CPS.
4) All (sub-) scales are negatively correlated to social well-being as measured according to the MDS-ISE and the RISE, scales measuring social engagement (an important prerequisite for social well-being), because challenging behavior will undermine others' willingness to fulfill the social well-being goals of the residents and therefore lead to lower levels of social well-being.

Methods

Measurement instruments

CHALLENGING BEHAVIOR – The new challenging behavior scale, the Challenging Behavior Profile (CBP) was validated against the Behavior Observation Scale for Psychogeriatric Inpatients (GIP), an observational behavior scale that is widely used and of known reliability and validity in Dutch long-term care facilities (Verstraten, 1988; De Jonghe, Kat, & De Reus, 1994). The GIP addresses social, cognitive, psychomotor and emotional behavior in elderly residents. As the Dutch GIP scale is not yet very well known internationally, we will here sum-

marize its psychometric properties. Just as the newly developed CBP, all five GIP scales addressed in this paper are positively skewed.

The 5-item GIP-non compliant behavior measures behavior regarding resistance against daily routine or against certain persons in the environment. The 8-item GIP-socially withdrawn behavior measures the absence of behavior directed towards others, and/or avoidance of interaction with others. The 5-item GIP-restless behavior measures wandering, not being able to sit still, and nervousness. The 5-item GIP-repetitive behavior scale measures behavior that is described as repetitive movements or vocalizations that do not have an apparent function. The 5-item GIP-dependent behavior measures asking for help or advice very often and trying to attract attention.

When first published, internal consistency (Cronbach's alpha) of these five GIP-scales was .61; .83; .68; .72; .67, respectively, and the inter-rater reliability (Pearson's r) was .68; .79; .75; .71; .72 respectively (Verstraten & Van Eekelen, 1987). In a validation study, internal consistency was .78; .84; .77; .72; .80, and average inter-rater reliability of the items (Cohen's weighted kappa) was .31; .45; .44; .56; .41, respectively. The internal consistency in this sample was .68; .87; .69; .79; .61. The correlation of the GIP-non compliant behavior scale with the NOSIE-30 sub-scale Irritability was .59 ($p<0.001$), and correlations of the GIP-socially withdrawn behavior with the NOSIE-30 sub-scales 'Social competence' and 'Social interest' were -.43 and -.81 ($p<0.001$), respectively (De Jonghe, Kat & De Reus, 1994).

Social engagement – Social engagement was measured according to the Index for Social Engagement (ISE) (Mor et al., 1995) and the Revised ISE (see Chapter 3), a revision of the original index. Both are observational instruments. The ISE is a 6-item observational scale that rates the resident's ability to take advantage of opportunities for social interaction and to initiate actions that engage her in the life of the home. Scores range from 0 to 6, with higher values representing more social engagement. Its internal consistency in this sample was .68. The RISE is more focused on factual interaction than the ISE and less on the resident's functional ability to engage. It also consists of 6 items, four of which are in the original index. The internal consistency of the RISE in this sample was .73.

Cognition – Cognition was measured according to the Cognitive Performance Scale (CPS), which is a 6-item hierarchical observational scale that rates cognitive impairment, with scores ranging from 0 (intact) to 6 (very severe impairment) (Morris et al., 1994). The CPS is scored according to a decision tree. Its reliability and validity have been demonstrated (Morris et al., 1994, Gruber-Baldini et al., 2000; Hartmaier et al., 1995). Its Cronbach's alpha in this sample was .74.

Statistical analyses – For this second sample, inter-rater kappa values of the items (Cohen, 1968; Landis & Koch, 1975) and intra-class correlation coefficients of the scale-scores (Shrout & Fleiss, 1979) were calculated to determine inter-rater reliability. The Landis and Koch classification (1975) was used to interpret both the kappa results and the icc coefficients (Montgomery et al, 2002) (.00 - .20 = slight, .21- .40 = fair, .41 - .60 = moderate, .61 - .80 = substantial, and .81 – 1.0 = almost perfect). Internal consistency was calculated by Cronbach's alpha (Cronbach, 1951). Cronbach's alpha is considered to be good if higher than .70, but should not be higher than .90 (Streiner & Norman, 1995). Principal component analysis was done to establish whether the scale's items have one underlying component, and principal axis factoring with varimax rotation was performed to provide insight into whether the four identified behavioral dimensions could be confirmed in this second sample. Validity was determined by testing the formulated hypotheses by calculating Spearman's correlation coefficients of the (sub-) scale-scores.

Results

Sample description

For the second analyses, a data set was used that consists of mds-assessments of 227 nursing home residents (Assess project). Dual assessments by a second rater were available for 151 residents. 211 to 218 complete gip sub-scales were available. The mean age of the 227 residents was 79.9 (52-100), 78% were female, and 54% suffered from moderate to severe cognitive problems (cps-score > 2).

Reliability

Table 2 shows the results on reliability estimates in the second sample. With the exception of Conflict, the sub-scales appeared to be sufficiently internally consistent in the second sample. Their squared weighted kappas were satisfactory, with only one item (E4ea: resisting care) having a kappa value below .4. The intra-class correlation coefficient was never below moderate, although the icc of Conflict and Withdrawal were somewhat low and the 95% confidence interval of Withdrawal included .35.

Table 2. Internal consistency (alpha) and inter-rater reliability of items (Kappa) and scales (ICC) of challenging behavior (sub-)scales in the second (validation) sample (N=227)

(sub-)scale (N_{range}: 224-226)			Alpha (N_{range} 197-226)	Kappa (N_{range} 147-151)		ICC[1] (N_{range} 147-149)	
	N_{Items}	Range of scale		Mean K	Range K	ICC	CI 95%[2]
Conflict	5	0-6	.53	.49	.34-.70	.59	.47-.68
Withdrawal	2	0-4	.78	.44	.44-.44	.48	.35-.59
R & R[3]	3	0-5	.66	.65	.57-.71	.80	.73-.85
Claiming	5	0-9	.75	.53	.43-.62	.68	.58-.76
Overall CBP	15	0-19	.78	.53	.34-.71	.75	.67-.81

1 ICC: Intraclass Correlation Coefficient
2 CI 95%: 95% confidence interval intra-class correlation coefficient
3 Restlessness & Repetition

The factor structure (see Table 3) was not as strong as in the first sample. In principal component-analysis, the 15 items did all load on the first factor with an eigenvalue of 4.03, explaining 27% of the variance with loadings from .21 to .71. However, five items had a loading below .40 (E1n, E4aa, E4ca, E4ea & F2a). To investigate whether the four sub-scales would emerge when rotating the factor-solution, we used principal axis factoring with the four identified dimensions and varimax rotation. The Withdrawal and Restless & Repetitive behavior sub-scales emerged with loadings ranging from .61 to .80, and .46 to .86 respectively. The items of the Claiming sub-scale loaded on one factor with loadings from .47 to .75, but it was difficult to distinguish the Conflict behavior sub-scale from the Claiming sub-scale. Whereas in the first sample only item E1d of the Conflict sub-scale loaded above .40 on the claiming factor, in the second sample E4ba and F2a also loaded on the claiming factor. Moreover, F2a did not load on the conflict factor.

Table 3. Factor structure of challenging behavior sub-scales in the second (validation) sample

Dimension	Item		Factor Structure				
			PCA[1]	PAF[2] with varimax rotation			
Conflict	E1d	*Repetitive persistent anger with self or others*	.71	.64	.13	~0	**.35**
	E4ba	*Verbally abusive behaviors*	.56	.49	.10	~0	**.24**
	E4ca	*Physically abusive behaviors*	.21	~0	.18	.11	**.25**
	E4ea	*Resists care*	.26	~0	~0	.10	**.63**
	F2a	*Conflict with or repeated criticism of staff*	.34	.46	-.14	~0	**~0**
Withdrawal	E1o	*Withdrawal from activities of interest*	.50	.14	.22	**.80**	~0
	E1p	*Reduced social interaction*	.52	.17	.10	**.61**	.35
R & R[2]	B5d	*Periods of restlessness*	.55	.33	**.47**	~0	.20
	E1n	*Repetitive physical movements*	.37	~0	**.86**	~0	~0
	E4aa	*Wandering*	.21	~0	**.46**	.20	~0
Claiming	E1a	*Negative statements*	.68	**.75**	~0	.13	~0
	E1b	*Repetitive questions*	.69	**.57**	.28	.18	~0
	E1c	*Repetitive verbalizations*	.70	**.59**	.13	.13	.25
	E1h	*Repetitive health complaints*	.56	**.50**	~0	.30	~0
	E1i	*Repetitive anxious complaints/concerns*	.49	**.47**	~0	~0	~0

1 Principal component analysis, 2 Principal Axis Factoring, 3 Restlessness & Repetition

Validity

Validity was assessed by testing the four hypotheses described earlier. Table 4 presents the results.

Hypothesis 1: The new sub-scales were significantly correlated to each other, but not very high (range .30- .49). This suggests they, indeed, can be considered as scales for separate constructs.

Hypothesis 2: The associations of the new sub-scales with the GIP-scales were optimal with their corresponding sub-scale (-s), as stated in the hypothesis. Each new sub-scale was correlated higher with its corresponding GIP-scale (-s) than the other new sub-scales were (read the Table horizontally). In addition, each GIP-scale was correlated higher with its corresponding new sub-scale than the other GIP-scales were (read the Table vertically), with the exception of one: GIP-

dependent behavior correlated about the same to the new Claiming sub-scale as GIP-restless behavior did (.23 & .24 respectively).

HYPOTHESIS 3: Apart from Claiming, the overall CBP and its sub-scales correlated positively to cognitive problems, thus: with increasing cognitive problems, challenging behavior increased.

HYPOTHESIS 4: As expected, the overall CBP and its four sub-scales correlated negatively to social engagement. Withdrawal, which by content is more or less the opposite of social engagement, correlated the highest to both social engagement scales (-.57 and -.57, respectively), and Claiming the lowest (-.21 and -.13, respectively).

Table 4. Correlations (Spearman's rho) of the measures considered in the hypotheses in the second (validation) sample (N_{range} 208-226)

Hypothesis	Measure	Conflict	Withdrawal	R & R[1]	Claiming	Overall CBP
1	Withdrawal	.33**				
	Restlessness & Repetition	.34**	.30**			
	Claiming	.49**	.29**	.30**		
	Overall CBP	.72**	.61**	.69**	.72**	
2	GIP-Noncompliant behavior	**.53****	.34**	.37**	.23**	.49**
	GIP-Socially withdrawn behavior	.24**	**.35****	.25**	-.01	.30**
	GIP-Restless behavior	.28**	.09	**.49****	.24**	.39**
	GIP-Repetitive behavior	.32**	.25**	**.47****	.17*	.40**
	GIP-Dependent behavior	.10	.02	-.08	**.23****	.09
3	CPS	.22**	.33**	.50**	.08	.42**
4	ISE	-.34**	-.57**	-.29**	-.21**	-.48**
	RISE	-.30**	-.57**	-.20**	-.13	-.40**

1 Restless & Repetition, * p<0.05, ** p< 0.01

Discussion

In this study, a reliable and valid behavioral scale was constructed, the Challenging Behavior Profile, which is available for all long-term care facilities using the MDS of the Resident Assessment Instrument. This scale is designed for better management of challenging behavior in long term care. It consists of four sub-scales, measuring the behavioral dimensions Conflict behavior, Withdrawal behavior, Restless & Repetitive behavior, and Claiming behavior. The (sub-) scales were found to relate significantly to other scales measuring the same constructs, and an increase in cognitive problems corresponded with more challenging behavior. Although the sum score on challenging behavior was higher in cognitively impaired residents, additional analyses showed that the strength of the

correlations with the comparison scales was about the same for residents with and without dementia. This suggests they can be used in the entire nursing home population.

The relationships of the new (sub-) scales with social engagement can be considered as an indication that challenging behavior does have an impact on (social) well-being, because social engagement is an important prerequisite for QOL (Mor et al., 1995). This is in agreement with the ideas of the SPF theory as explained in the introduction. Other researchers in the field do acknowledge that challenging behavior may have to do with unmet needs (see Cohen-Mansfield, 2001). However, in the 'unmet needs' model, unmet needs are the cause of the behavior. Our approach, on the other hand, is about the consequences of the behavior for the well-being of the resident. The present approach to challenging behavior will let nursing staff and other caregivers understand better why it is an important threat to the residents' well-being, why it is important to measure this behavior, and also, that their own behavior can play an important role in limiting the effect of the behavior on social well-being. They can, for instance, be trained to continue meeting the residents' needs independent from resident behavior. By starting from the viewpoint that challenging behavior primarily has to do with well-being, and by only using behavioral items, we were able to systematically select items and distinguish scales based on meaningful (behavioral) content, instead of using a categorization based on, for instance, physical versus verbal behaviors (Cohen-Mansfield & Billig, 1986; Beck et al., 1998).

Although the sub-scales were easily distinguishable in the first sample, internal consistency and factor analyses in the second sample showed less distinct relationships between the items. In the second sample, the Conflict subscale was difficult to distinguish from the Claiming sub-scale and had a low alpha. However, a check of 151 MDS-assessments that were used for kappa and ICC calculation (assessed by a second rater), revealed an alpha of Conflict of .68 (and of .82 for Withdrawal; .70 for Restlessness & Repetition; .75 for Claiming and .82 for the overall CBP). Also, the factor structure of the second assessments was stronger (only item E4aa loaded below .40 on the first factor, and the Conflict and Claiming sub-scales were better discernable), although item F2a (conflict with or repeated criticism of staff) still did not load on the conflict-dimension. Further research on different samples should therefore study the appropriateness of using item F2a in the Conflict sub-scale and confirm whether the Conflict can be held separate from the Claiming sub-scale.

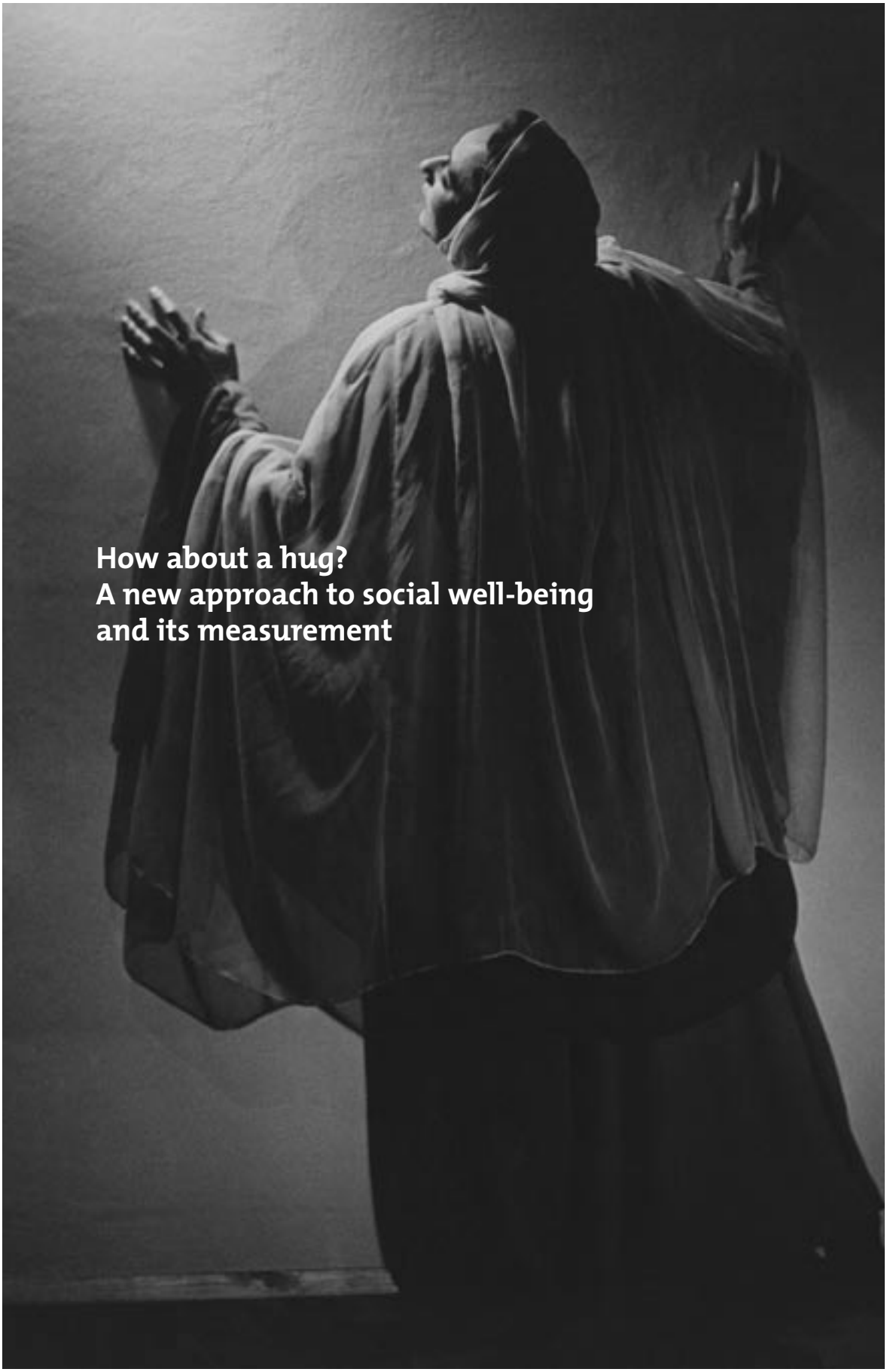
In contrast with the other three sub-scales, Claiming did not relate to the CPS (cognition). This may be attributable to the fact that these behaviors are also considered as indicators of depression, and thus may frequently be scored by residents without cognitive impairment. Another noteworthy finding is that the GIP-dependent behavior scale did not have strong relationships with the

new (sub-) scales. This may have been caused by the low internal consistency of the GIP-dependent behavior (alpha of .61), which may also explain why the new Claiming sub-scale did not correlate obviously stronger with the GIP-dependent behavior scale than with the other GIP-scales.

A limitation of the study may be that by using the MDS as a starting point, although a broad range of behavior was created, it is not ruled out that we have missed some important behavioral features, such as suspicious behavior. Further research should therefore include other, non-MDS, items. Notwithstanding, one great advantage of using MDS items for a behavior scale is that thousands of long term care facilities could have instant access to a specific profile of challenging behavior of their residents that requires no additional collection of data. If followed by adequate interventions (see for instance Cohen-Mansfield (2001; 2003) for a review), this can have a large positive impact on the quality of life of residents of nursing homes worldwide.

The approach described in this chapter focuses primarily on the social well-being of the resident. Nonetheless, the people around the resident are burdened by challenging behavior as well. A necessary following step is therefore to develop a means to determine whether the challenging behavior of an individual resident is experienced as a problem by the involved (nursing) staff, other residents or visitors. The importance of this step has already been recognized in challenging behavior research, for instance in the Neuro-Psychiatric Inventory of Cummings et al. (1994; 1997). Separate from the threat to the resident's well-being, this can in itself be a valid reason to intervene in challenging behavior. Yet, such interventions may also focus on the people around the resident instead of on the resident.

In conclusion, a measurement scale for challenging behavior (the CBP) was successfully developed, which showed to be reliable and valid. This approach to challenging behavior may be the basis of a new method for the clinical management of challenging behavior in long term care, and the scale that was constructed may be especially useful as it is easily accessible for many long term care facilities. The impact that challenging behavior may have on both caregiver distress and resident well-being makes the CBP and its sub-scales an important contributor to the suite of clinical MDS-scales.



How about a hug?
A new approach to social well-being and its measurement

Chapter 6 is submitted as Gerritsen, D.L., Steverink, N., Frijters, D.H.M., Ooms, M.E., Ribbe, M.W. How about a hug? A new approach to social well-being and its measurement in the nursing home

Chapter 6

How about a hug? A new approach to social well-being and its measurement

The quality of life of nursing home residents is being given increasingly more attention in nursing home practice and scientific research. Traditionally, the care provided has been problem-oriented and medicine based. Therefore, most instruments that have been developed to assess nursing home residents focus on functional impairment, such as problems in performing the Activities of Daily Living (ADL) and in cognition. In the 1970s, care started to focus more on the psychological and social well-being of the residents (Finnema, Dröes, Ribbe, & Van Tilburg, 2000). Subsequently, the development and use of measures of depression and challenging behavior has increased. However, few of the instruments that have been developed measure *well-being* as opposed to deficiencies and disabilities. Nevertheless, to obtain insight into quality of life it is necessary to measure positive concepts, since the absence of, for instance, challenging behavior or loneliness does not automatically imply that a resident is happy or socially content.

As stated by the Social Production Functions theory (SPF theory) (Lindenberg, 1996; Steverink, Lindenberg, & Ormel, 1998; see Chapter 2), overall quality of life (i.e. psychological or subjective well-being) is achieved through the realization of physical and social well-being, of which the latter is the subject of this chapter. The theory indicates that social well-being is the result of achieving three basic human needs or goals: affection, behavioral confirmation and status. *Affection* refers to being loved as a person by oneself and by others and is, for instance, achieved by social support and feeling close to someone. *Behavioral confirmation* refers to doing the right thing in the eyes of oneself and others and is, for instance, achieved by being liked because others appreciate one's behavior. S*tatus* is the accomplishment of appreciation from oneself and others as a consequence of having positive distinctive characteristics and is, for instance, achieved by having

unique skills. It is thought that the more a person achieves of each goal, the more social well-being she will have.

According to the SPF theory, the people around the resident are of vital importance, since they can give the resident the affection, behavioral confirmation or status she wants and needs. This implies that when measuring social well-being, it may also be necessary to measure whether others actually provide affection, confirmation and status, instead of only measuring the behavior of the resident. For instance, a resident who is engaged in social activities scores positively on an observational scale of social behavior, but it is possible that the necessary positive behavior of others (confirming the resident's behavior or showing affection) does not occur. Therefore, this paper describes the development of a new scale that measures 1) the behavior or characteristics of the resident that, according to the SPF theory, will generally lead to positive social reactions from others, and 2) the behavior of others that will generally fulfill the resident's needs with regard to social well-being. The instrument should encompass the three dimensions (i.e., goals) of social well-being, if possible by measuring them separately.

The remainder of this paper consists of three sections. The first section describes the composition and justification of a set of items with an appropriate response-scale, followed by scale-analyses and the determination of internal consistency. In the second section the validity of the resulting scale is assessed in a second sample. The characteristics of this second sample are described and the construct validity of the scale is examined. In the final section, the results are discussed.

Scale design

Composition and justification of the item set

To develop an instrument that is easy to use in daily nursing home practice, the aim was to make an observational scale that was suitable for the entire nursing home population and could be scored by nursing staff. Items on the behavior of others towards the resident (GET-items) and items on the behavior of the resident towards others (AIM-items) were considered. Measuring a resident 'getting' affection, behavioral confirmation or status follows directly from the SPF theory. Examples of GET-items are 'How often does the resident get a compliment for her looks?' and 'How often does the resident get a hug?'. However, as GET-items involve positive behavior of the nursing staff, they might be susceptible to socially desirable answers. Therefore, it was also necessary to formulate so-called AIM-items that might be just as effective as GET-items, and perhaps more reliable. AIM-items refer to resident behavior or characteristics that, according to the SPF theory, stimulate and influence the resident's well-being through making people around the resident more likely to fulfil the resident's social needs. Examples of

AIM-items are 'How often does the resident help other residents with something?' and 'How often does the resident show appreciation to the nursing staff?'.

On the basis of the three dimensions of social well-being of the SPF theory, 28 items were initially formulated. The specific subject of each item was based on our clinical observations of daily interaction in four nursing homes. Subsequently, eleven individual key informant interviews were held with nurses, psychologists and physicians in the nursing homes. In these interviews the subject and formulation, as well as the response-scale of the items, were discussed. After each interview any adaptations that had been suggested were added to the next interview. This process resulted in a final set of 27 items (12 affection items, 9 behavioral confirmation items, and 6 status items). For each social well-being dimension, both GET- and AIM-items remained.

To avoid a situation in which the nursing staff would have to judge themselves or their direct colleagues, and to control for socially desirable answers, the items were depersonalized by referring to all people around the resident instead of the respondent alone. For instance, 'How often do you give the resident a hug?' was replaced by 'How often does the resident get a hug (from nursing staff or others)?'. Although this makes the questions more difficult to answer, our key informants deemed it necessary.

The response-scale of the items was also discussed in the interviews. The response-scale pertained to two scaling methods. One group of items measures behavior frequencies; the other group measures the absence or presence of behavior or of personal characteristics. An important advantage of frequency-items is that they are likely to be more responsive to change. On the other hand, they are more difficult to assess. The response-scale of the frequency-items that resulted from the interviews is as follows: 1) once a month or less; 2) once a week; 3) several times a week; 4) once a day; 5) several times a day or the entire day; and finally, 6) not relevant. Most items on the presence/absence of behavior or characteristics were dichotomous. Where it was considered necessary, an additional response-category 'not sure' or 'in-between' was added, leaving a group of items with 2 or 3 response-categories. For affection and behavioral confirmation there were GET- and AIM-items with frequency and with presence/absence response-categories. For status, no frequency items remained.

Description sample 1

The items were tested in a population of nursing home residents in three nursing homes in the Netherlands (Frijters, Gerritsen, & Steverink, 2003). Members of the nursing staff assessed all 306 residents in the three facilities. To establish intra-rater reliability, one nurse assessed 154 of these residents twice with a two-week interval; to establish inter-rater reliability, two different nurses both

assessed the other 152 residents. In total, 57 raters were involved in the double assessments. The average age of the 306 residents was 78.7 years (range: 24 to 99 years) and the distribution of gender was 70% female and 30% male. These characteristics largely resemble those of the Dutch nursing home population (Prismant & Arcares, 2002).

Scale construction

The scale-analyses involved four steps. First, if the 'not relevant' category (response-category 6) of the 12 frequency items contained more than 20 % of all responses on an item, the item was excluded. In the second step, all remaining items were entered into internal consistency analyses. The items for the three social well-being dimensions of affection, behavioral confirmation and status were analyzed separately. In addition to determining Cronbach's alpha (Cronbach, 1951) and optimizing the properties of the scale by removing items until an optimal alpha value was reached, two other considerations with respect to content were applied: A) items grouped in one dimension of social well-being that correlated more to items of another dimension than to items of their own dimension were excluded from the analyses in order to separate the three dimensions: B) if it appeared that a scale with three sub-scales could be constructed, for the sake of clarity and ease of assessment, each sub-scale should, if possible, consist of items with one type of response-scale only; either frequency items with 6 categories or presence/absence items with 2 or 3 categories. As there were two groups of items (with response-scales of 6 categories and 2/3 categories), additional internal consistency analyses were performed in which the 6-category items were recoded into 3-category items. The reason for this was to find out whether 6-category items appeared stronger in the analyses than 2/3-category items because they had more response-categories.

In the third step, the intra-rater reliability and inter-rater reliability of the scales and the individual items were determined by calculating the Intraclass Correlation Coefficient (ICC) of the scale (Shrout & Fleiss, 1979) and the kappa values of the items (Cohen, 1968). Factor analyses were performed in the fourth and final step.

Non-relevancy

Two affection items and three behavioral confirmation items (5 of the 12 items with 6 response-categories) had a not-relevant category (category 6) that contained more than 20% of the responses, and were excluded from the scale construction. Of the remaining 7 items, the not-relevant category was recoded as missing, thus leaving them as 5-category items.

Reliability: Internal Consistency

AFFECTION: Of the 10 remaining items concerning affection, two correlated more to three status items than to other affection items and one correlated more to four confirmation and three status items than to other affection items. Therefore, they were excluded from the analyses. This left seven items (five 5-category items and two 2/3-category items). Cronbach's alpha for these was .60, and the mean inter item correlation (miic) was .17. This could be improved upon significantly by omitting four items. The three remaining items, all 5-category items, formed a scale with a Cronbach's alpha of .77 and a miic of .53 (see Table 1). Additional analyses, in which the 5-category items were recoded into 3-category items, produced approximately the same results.

BEHAVIORAL CONFIRMATION: After the removal of three items with a large not-relevant category, six items remained. Of these, none correlated more to affection items or status items than to either of the other behavioral confirmation items. They had an alpha of .53 and a miic of .21. Additional analyses, with the two 5-category items recoded into 3-category items, showed that the two recoded items were the weakest of the scale. After these were discarded, a scale of three items (2/3 response categories) remained, with a Cronbach's alpha of .82 and a miic of .60 (see Table 1).

STATUS: Also for status, no items were identified that correlated more to affection items or behavioral confirmation items than to either of the other status items. The six status items (all 2/3-category items) had an alpha of .28 and a miic of .08, which could be increased by removing three items, leaving a scale of three items (2/3 response categories) with an alpha of .69 and a miic of .43 (see Table 1).

OVERALL SOCIAL WELL-BEING: The three resulting scales also formed an internally consistent scale of nine items with an alpha of .74 and a miic of .30. This means that not only the dimensions, but also overall social well-being can be measured.

Reliability: Intra-rater and Inter-rater Reliability

The third step involved the calculation of intra-rater and inter-rater-reliability of the scales (ICC's) and their items (kappa's) (see Table 1 for both). Cohen's squared weighted kappa was used on items with more than two response-categories, and the Landis and Koch classification (1975) was used to interpret both the kappa results and the ICC coefficients (Montgomery et al., 2002) (.00 - .20 = slight, .21- .40 = fair, .41 - .60 = moderate, .61 - .80 = substantial, and .81 – 1.0 = almost perfect). Intra-rater reliability of the items ranged from moderate to substantial (kappa range .53 - .79). The inter-rater reliability was moderate in 6 of the 9 items (.40 - .54), and fair in 3 (.32, .39, .40) (see Table 1). The intra-rater ICC

Table 1. Internal consistency (alpha), intra- and inter-rater reliability of items (Kappa)

Scale	Item	N[3]	Alpha (miic)[4]
			N_{range} = 252-306
Affection	1 How often does this resident show appreciation towards nursing staff?	5	.77 (.53)
	2 how often does this resident get a hug (or a cuddle, etc) form the nursing staff and others?	5	
	3 how often is there humor in the contact with this resident (nursing staff and others)?	5	
Behavioral confirmation	4 does this resident usually try to take others into account?	2	.82 (.60)
	5 is this resident concerned about others?	2	
	6 does this resident usually try to keep to the agreements made?	2	
Status	7 does this resident have a positive presence on the unit? (f.i. humor, always happy, a special talent?	2	.69 (.43)
	8 is this resident popular with the other residents?	3	
	9 is this resident popular with the nursing staff?	3	
Social well-being			.74 (.30)

of the scales was substantial or almost perfect and ranged from .74 to .83; the inter-rater ICCs were moderate, and ranged from .53 to .55.

Factor-analyses

Factor-analyses were performed in the fourth step. In principal component-analysis (N=252), the nine items that resulted from steps 1 to 3 all loaded on the first factor with an eigenvalue of 3.43, explaining 38% of the variance with loadings from .43 to .70. A second factor with an eigenvalue of 2.06 also emerged, on which the items on behavioral confirmation loaded (loadings from .54 to .74; two of the three loaded higher on the second factor than on the first), explaining 23% of the variance. Principal axis factoring with three factors and varimax rotation was used to further investigate the manifestation of the theoretical concept in the scales. The three sub-scales emerged (the third factor having an eigenvalue of .83; total variance explained was 70%) on three distinct factors, on which none

and scales (ICC), and factor structure of the new scales

Kappa (Pa)[1]		ICC[2]		Factor structure			
N_{range}=127-151		N_{range}=106-151		N=252			
Intra-rater	Inter-rater	Intra-rater	Inter-rater	PCA[5]	PAF, varimax rotation6		
.76 (.96)	.44 (.90)	.83	.52	.68	.16	**.62**	.26
.60 (.94)	.39 (.91)			.46	-.19	**.67**	.19
.79 (.96)	.44 (.92)			.68	~0	**.84**	.18
.70 (.85)	.32 (.66)	.77	.55	.58	**.73**	~0	.17
.67 (.84)	.43 (.71)			.61	**.76**	.15	.12
.74 (.87)	.54 (.77)			.43	**.78**	-.11	.12
.53 (.80)	.40 (.74)	.74	.55	.68	.15	.40	**.49**
.69 (.93)	.50 (.88)			.65	.32	.13	**.59**
.70 (.95)	.53 (.90)			.70	.12	.37	**.63**
		.78	.53				

1 N resp cats= number of response categories
2 miic=mean inter item correlation
3 Pa = Percentage agreement
4 ICC= Intraclass Correlation Coefficient
5 PCA=principal component analysis,
6 PAF varimax rotation= principal axis factoring with varimax rotation

of the items of the other sub-scales loaded above .40. Loadings on the factors are presented in Table 1. In spite of the afore-mentioned low kappa value of two of the items, they appear to be important components of the scale, which is illustrated by their factor-loading. They have, therefore, been retained in the scale.

Given that the items of each dimension loaded on one joint factor, and together formed an internally consistent scale, sum-scores can be calculated for the three sub-scales. Because it was not possible to construct three scales with the same response-categories, for summation it is necessary to recode the sum-scores of

each sub-scale by multiplying the score for behavioral confirmation and status by 2 and dividing the score for affection by 2 (see Appendix 3). Each sub-scale then has a theoretical range from 0 to 6. The overall social well-being scale ranges from 0 to 18 and has a normal distribution. The scores on the affection-scale of the present sample range from 0 to 6, with a mean value of 3.2, scores of the behavioral confirmation scale range form 0 to 6, with a mean value of 2.9, and scores of the status-scale also range from 0 to 6, with a mean value of 2.3. The distribution of the behavioral confirmation sub-scale is somewhat negatively skewed, but the sub-scales of affection and status have a normal distribution (the scales are presented in Appendix 3).

The calculation of Spearman's correlation coefficients between the scales showed that all three were significantly correlated (see Table 2), but that affection was somewhat less correlated to the total scale (rho=.61) than behavioral confirmation (rho=.78) and status (rho=.79). Affection was not significantly correlated to behavioral confirmation (rho=.11) but considerably correlated to status (rho=.53). Behavioral confirmation and status were also correlated (rho=.38).

In conclusion, it was possible to make three reliable and parsimonious scales for the three social well-being dimensions, each consisting of three items. The first, measuring affection, consists of frequency items (5 response categories). The scales measuring behavioral confirmation and status consist of presence/absence items. Together, they measure overall social well-being.

Validity

This section of the paper focuses on the properties of the newly developed scales in a second sample of residents. Internal consistency is determined and the factor structure is examined. Construct validity is determined by testing the following three hypotheses:

1) As social engagement is a positive social construct (and a prerequisite for social well-being), the new scales are expected to correlate positively to social engagement.
2) As socially withdrawn behavior and apathetic behavior are negative social constructs that reflect social disengagement, the new scales should correlate negatively to socially withdrawn behavior and apathetic behavior.
3) The *patterned change* prediction of the SPF theory (Steverink et al., 1998) states that when people lose many resources to attain social well-being, which applies to most nursing home residents, status will be the first social well-being goal that has to be released. When further losses occur, behavioral confirmation will be next to go, while affection can be maintained relatively easily. Given this pattern of change in the dimensions of social well-being, the hypothesis is that with increasing cognitive and ADL

impairments, the total score for social well-being will consist of relatively more affection than status and behavioral confirmation respectively.

Methods

The nursing staff in 8 nursing homes in the Netherlands assessed residents according to the 3 social well-being scales. In this second sample the nursing staff also used 5 other observational instruments, which are described below. All questionnaires for a resident were assessed within one month.

Measurement instruments

SOCIAL BEHAVIOR SCALES – The new social well-being scales were used to assess affection, behavioral confirmation and status.

Social engagement was measured according to the Index for Social Engagement (ISE) (Mor et al., 1995) and the Revised ISE (RISE; see Chapter 4), a recent revision of the original index. Both are observational instruments. The ISE is a 6-item observational scale that rates the resident's ability to take advantage of opportunities for social interaction and to initiate actions that engage her in the life of the home. Scores range from 0 to 6, with higher values representing more social engagement. Its internal consistency in this sample was .68. The RISE is more focused on factual interaction than the ISE and less on the resident's functional ability to engage. It also consists of 6 items, four of which are in the original index. The internal consistency of the RISE in this sample was .73.

Social disengagement was operationalized as socially withdrawn behavior and apathetic behavior. Both types of behavior are measured according to two sub-scales of the Behavior Observation Scale for Geriatric Inpatients (GIP), a behavior observational scale that is widely used in Dutch nursing homes to monitor the status of residents (Verstraten, 1988; De Jonghe, Kat, & De Reus, 1994). The GIP describes behavioral, cognitive and affective symptoms in elderly cognitively impaired residents.

The 8-item GIP-socially withdrawn behavior measures the absence of behavior directed towards others, and/or avoidance of interaction with others. When first published, internal consistency (Cronbach's alpha) of the GIP-socially withdrawn behavior was .83, and inter-rater reliability (Spearman's rho) was .79 (Verstraten & Van Eekelen, 1987). In a validation study, internal consistency was .84, average inter-rater reliability of the items (Cohen's weighted kappa) was .45, and correlations with the NOSIE-30 subscales 'Social competence' and 'Social interest' were -.43 and -.81 ($p<0.001$) respectively (De Jonghe, Kat & De Reus, 1994). Internal consistency in this sample was .87.

The 6-item GIP-apathetic behavior measures lack of interest in or unresponsiveness to activities or persons. When first published, internal consistency (Cronbach's alpha) of the GIP-apathetic behavior was .79, and inter-rater reliabil-

ity (Spearman's r) was .76 (Verstraten & Van Eekelen, 1987). In a validation study, internal consistency was .75 average inter-rater reliability of the items (Cohen's weighted kappa) was .37. (De Jonghe, Kat & De Reus, 1994). Internal consistency in this sample was .77.

FUNCTIONING SCALES – *Cognition* was measured according to the Cognitive Performance Scale (CPS), which is a 6-item hierarchical observational scale that rates cognitive impairment, with scores ranging from 0 (intact) to 6 (very severe impairment) (Morris et al., 1994). The CPS is scored according to a decision tree. Its reported Cronbach's alphas range from .70 to .88 (Morris et al., 1994; Gruber-Baldini et al., 2000), and its validity has been demonstrated (Hartmaier et al., 1995). Cronbach's alpha in this sample was .74.

ADL *functioning* was measured according to the ADL Self- Performance Hierarchy (ADL-SPH), an observational ADL-dependence scale that measures resident self-involvement in the personal activities of daily life (Morris, Fries, & Morris 1999). It is scored according to a decision tree, with 7 scale-categories ranging from 0 to 6. When it was introduced, reported psychometric properties were kappa values of the items ranging from .87 to .94 (inter-rater reliability), and an internal consistency (Cronbach's alpha) of .90. Cronbach's alpha in this sample was .84.

Statistical analyses

For this second sample, the internal consistency of the new scales was calculated again. The factor structure in this sample was also examined. Construct validity was determined by testing the three hypotheses. The first two were tested by calculating Spearman's correlation coefficients of the scale-scores. For the third, variables were constructed for the proportion of each sub-scale score of the total social well-being score, and the relationships with the scores on the CPS (cognition) and the ADL-SPH were studied by calculating Spearman's correlation coefficients.

Results

Description Sample 2

Sample 2 consisted of 165 residents in 8 nursing homes in the Netherlands. Of these, 78% was female, the mean age was 79 years (range: 52-96), and 69% had completed elementary education at the most. In comparison to the first sample, there were more females in the second sample.

The overall social well-being scale (N=118) ranged from 1 to 17, and had a normal distribution. Scores of the affection scale (N=127) ranged from 0 to 5.5, with a mean value of 3.1, scores of the behavioral confirmation scale (N=162) ranged from 0 to 6, with a mean value of 3.7, and scores of the status scale (N=159)

also ranged from 0 to 6, with a mean value of 2.5. In this second sample the distribution of the behavioral confirmation sub-scale was also negatively skewed, and the distributions of the other two sub-scales were normal. Because the not-relevant category still existed during data collection, the overall social well-being scale and the affection scale have smaller numbers. The Spearman's correlation coefficients of the three sub-scales and the total social well-being scale were largely similar to those in the first sample (see Table 2). The only substantial difference between the results of the two samples was the smaller correlation between status and affection (.27 compared to .53 in the first sample).

Table 2. Correlations (Spearman's rho) between the new scales, in the two samples (N_{range} Sample 1:252-307; N_{range} Sample 2:118-154)

	Sample 1			Sample 2		
	Social well-being	Affection	Behavioral confirmation	Social well-being	Affection	Behavioral confirmation
Affection	.61**			.48**		
Behavioral Confirmation	.78**	.11		.82**	.15	
Status	.79**	.53**	.38**	.81**	.27	.44**

** p< 0.01

Scale Properties

Internal consistency – Table 3 shows that all alphas were lower in the second sample than in the first sample, especially for the sub-scale affection, which had an alpha of .77 in the first sample (see Table 1), compared to an alpha of .60 in the second sample.

Factor Structure – In principal component-analysis (N=118), the nine items all loaded on the first factor with an eigenvalue of 3.07, explaining 34% of the variance with loadings from .31 to .72. A second and third factor with eigenvalues of 1.69 and 1.2, respectively, also emerged, together explaining an additional 32% of the variance. To investigate whether the three scales would emerge when rotating the factor-solution, we used principal axis-factoring with the three identified factors and varimax rotation. The three sub-scales emerged on the three factors, on each of which the items of the other sub-scales loaded below .37. Behavioral confirmation was the first factor (loadings between .57 and .81), status was the second (.61 - .67), and affection the third (.52 - .65).

Table 3. Internal consistency (alpha) of the new scales in the second sample, and correlations (Spearman's rho) with social engagement and disengagement

	Internal consistency		Correlations							
			Social engagement RISE		Social engagement ISE		Social withdrawal		Apathy	
	α (miic)[1]	N	rho	N	rho	N	rho	N	Rho	N
Social well-being	.68 (.25)	118	.46**	81	.38**	82	-.58**	118	-.48**	118
Affection	.60 (.34)	127	.10	87	.01	88	-.15	127	-.19*	127
Behavioral confirmation	.76 (.51)	162	.53**	110	.47**	111	-.61**	161	-.50**	158
Status	.65 (.40)	159	.28**	110	.22*	111	-.40**	158	-.32**	159

1 (miic) = mean inter item correlation * p< 0.05; ** p< 0.01

Construct Validity – Construct validity was assessed by testing the three hypotheses described earlier. Table 3 presents the results regarding hypotheses 1 and 2, Table 4 contains the results regarding hypothesis 3.

1) The scales are positively correlated to social engagement. Overall social well-being, as well as behavioral confirmation and status, were significantly positively related to social engagement, as expected. However, affection was not related to social engagement.

2) The scales are negatively correlated to behaviors of social disengagement (socially withdrawn behavior and apathetic behavior). The relationships were all negative, although the correlation coefficients for affection were not very strong.

Table 4. Relationship of cognitive and ADL impairment with each new sub-scale's proportion of the total social well-being score (Spearman's rho; N_{range}: 105-117)

	Cognitive impairment	ADL impairment
Affection/social wb	.45**	.13
Behavioral confirmation/ social wb	-.40**	-.26**
Status/social wb	-.09	.02

** p< 0.01

3) The total social well-being score will consist of relatively more affection than status and behavioral confirmation, with increasing cognitive and ADL prob-

lems. The proportion of affection in the total social well-being score significantly increased with higher CPS-scores (i.e. more cognitive impairment), whereas the proportion of behavioral confirmation decreased. The proportion of status did not change. With increasing ADL impairment (higher ADL-SPH scores), the same trend was visible in the proportion of affection versus behavioral confirmation, but it was less substantial.

Discussion

Our findings suggest that we have been able to construct a measure of social well-being in nursing home residents, assessing both the overall concept as well as the three dimensions of social well-being in line with the SPF theory. The overall scale, called the Social Well-being Of Nursing home residents scale (SWON-scale), consists of nine items that have good intra-rater reliability and modest inter-rater reliability. The ICC and the internal consistency of the new scale are also satisfactory. The items all load on one factor corresponding with the overall social well-being dimension. Moreover, for each of the dimensions of affection, behavioral confirmation and status, it was possible to construct a 3-item sub-scale that is internally consistent. The intra-rater reliability of the sub-scales is good, and the inter-rater reliability is modest. After rotation in factor-analyses, the sub-scales appeared to load on three different factors, which is further testimony that the three theoretically specified sub-dimensions are empirically valid. The reliability results were neither different for the 2/3- and 5-category items, nor for GET- and AIM-items, although more AIM-items survived scale analyses. Reliability is acceptable for both of the samples, although the results were better in the first. Since the second sample, in which the kappa values of the items were calculated, was rather small, additional research is recommended.

Because of its substantial and significant correlation to other positive and negative indicators of social well-being, the construct validity of the SWON-scale appears to be good. The relatively higher correlation with socially withdrawn behavior than with apathetic behavior is not surprising, because the former has a more social orientation. The construct validity of the sub-scales is also satisfying. The relatively strong relationship of the behavioral confirmation sub-scale with the conventional measures of social engagement (ISE) and disengagement (socially withdrawn and apathetic behavior) may be attributable to the fact that these measure the kind of behavior that yields behavioral confirmation. The sub-scale on affection has no relationship with the ISE, and an obviously smaller correlation with socially withdrawn and apathetic behavior. Yet, the sub-scale on affection appears to be valid: decline in ADL, but especially in cognition, correlates positively with a relative increase in the proportion of affection and a relative decrease in the proportion of behavioral confirmation in the overall social well-being score. Affection thus seems to be especially important in the

social well-being of residents with severe impairments. In residents with less impairment, behavioral confirmation is the more important contributor to social well-being. The "patterned change" prediction of the SPF theory was, therefore, largely confirmed.

All things considered, the results of the sub-scale on affection are somewhat inconclusive. It was found to have good internal consistency in the first sample (.77) but not in the second (.60), and no strong relationships were found with the conventional positive and negative indicators of social well-being, whereas the results on the third hypothesis did point to validity. Apparently, affection becomes relatively more important as cognition declines. Additional analyses show that the sub-scale on affection has a small but clear positive correlation to cognitive deterioration (rho .13), whereas status and behavioral confirmation are negatively correlated to cognition (rho -.26 and -.48 respectively). In addition, the ISE has a known negative relationship with cognitive deterioration (Mor et al., 1995), which has been confirmed in this sample (rho -.52). Thus, the findings suggest that even if a resident is no longer cognitively able to actively participate in the life of the ward, she can still get affection. When a resident actively disengages (socially withdrawn behavior), and especially when she is hard to reach (apathetic behavior), she will definitely have less opportunities to achieve behavioral confirmation and status, and the exchange of affection will, in these circumstances, also become less frequent. Thus, although it is necessary to study the possibilities of improving the reliability of the affection sub-scale, its distinct relationships with the other scales are understandable and suggest that it is valid.

Concluding, these first results concerning the SWON-scale and its subscales suggest they are valuable new measurement instruments in nursing home practice. They focus on social well-being dimensions that are present in daily nursing home life, but have, until now, not received structural and explicit attention, and will therefore have been provided arbitrarily. With use of these instruments, these social well-being dimensions become important care targets for all residents. The scales identify residents whose social well-being is at risk, and can be used to evaluate interventions to improve social well-being. Affection is an obvious target of intervention in cognitively impaired residents. For cognitively more intact residents, behavioral confirmation may be an additional target. The sub-scale on status can be important when, for instance, a resident identifies strongly with earlier roles. To measure social well-being, however, the resident's wishes and needs should be assessed on all three social well-being dimensions together. For a resident who might not want affection from the nursing staff, but would prefer a more distant relationship, more attention should be paid to behavioral confirmation and status.

Measurement of social well-being relates to new emotion oriented approaches in long term care, in which an attempt is made to link up with the experiences and perceptions of the resident. Expressing affection, endorsing the resident's behavior and supporting the resident's initiatives are important targets in this approach (Finnema et al., 2000). By including the behavior of people around the resident, the scales draw attention to the social attitudes and skills of both care-providers and residents.

The measurement of quality of life in nursing homes through self-report: the role of cognition

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Chapter 7

The measurement of quality of life in nursing homes through self-report: the role of cognition

Over the past decades, quality of life (QOL) has become a focal point in scientific research and clinical practice. Although researchers disagree on the dimensions (i.e. domains) that make up QOL, the general consensus is that quality of life measurement should focus on the subjective experience of the individual, rather than on a more objective approach. This implies that the individual in question is the most valid source of information (Selai & Trimble, 1999; Novella et al., 2001). However, nursing home residents may not, or no longer, be able to respond to self-report measures, which complicates the assessment and monitoring of a resident's QOL across time (Logsdon & Albert, 1999; Whitehouse, 1999). It would, therefore, be helpful to know which scales can be applied to nursing home residents with varying degrees of cognitive impairment.

QOL has emerged as a paramount concept in the care and treatment of people with dementia, which is the most common cause of cognitive impairment in the elderly (Logsdon, Gibbons, McCurry & Teri, 2002; Whitehouse, 1999). Establishing QOL in demented patients, however, is considered to be 'challenging' by many researchers in this field, for a number of reasons (Logsdon et al., 2002; Logsdon & Albert, 1999; Selai & Trimble, 1999; Selai, Trimble, Rossor, & Harvey, 2001; Lawton, 1997; Whitehouse & Rabins, 1992; Volicer & Bloom, 1999). Patients with dementia lose the cognitive ability to comprehend questions, reflect upon, or communicate on their subjective state (e.g. Logsdon et al., 2002; Selai & Trimble, 1999; Albert, 1997). Behavioral and other non-cognitive symptoms, such as restlessness and delusions, may impede the administration of QOL scales and, according to some researchers, also the validity of QOL ratings (e.g. Selai & Trimble, 1999). Furthermore, what patients consider to be most important for their QOL may be different in earlier and later stages of dementia (e.g. Whitehouse & Maslow, 1997;

Logsdon et al., 2002). For instance, preservation of intellectual capacity may be very important in the early stages, whereas comfort may be of primary importance in the later stages. Finally, the living situations of dementia patients will often change as the disease progresses, and this may play an important role when assessing QOL (Logsdon & Albert, 1999). Different environments pose different opportunities and challenges for a person's QOL and the item content of measurement scales may not be relevant in an institution. So, despite its high clinical relevance, measurement of subjective QOL in patients with cognitive impairment poses serious problems with regard to (content) validity and reliability.

Although self-report is a complex process of introspection and evaluation (Selai & Trimble, 1999), research has asserted that moderately demented patients still can report on their QOL, even when they have poor insight into and awareness of their dementia (Brod, Stewart, Sands & Walton,1999; Logsdon et al., 2002; Kane et al., 2003; Mozley et al., 1999). According to Kane et al. (2003), 60% of the nursing home population would be able to reliably report on their QOL. To establish which residents are able to self-report validly, several measurement instruments incorporate means to ensure that the residents understand the questions (Brod et al, 1999; Kane, 2003).

Most scales measure separate dimensions of QOL (Ready & Ott, 2003). This has the advantage of a higher responsiveness to change than a measure for overall QOL. However, overall QOL is an attractive outcome that can be measured as a single subjective result of weighing unspecified dimensions that are considered to be relevant by the patient. The administration is also less burdening, which is an important factor in a very frail elderly population. Therefore, many researchers (also) use a single overall measure (e.g. Brod et al., 1999; Logsdon & Albert, 1999).

In our approach to QOL (Lindenberg, 1996; Steverink et al., 1998; see Chapter 2), overall QOL is represented by subjective (i.e. psychological) well-being, and is seen as the result of physical well-being and social well-being. Given this, scales for subjective (psychological) well-being can be used as overall QOL scales. Although not always considered as the central outcome, psychological well-being is an important dimension of QOL in many other approaches (Lawton, 1991; Lawton, Van Haitsma & Klapper, 1996; Ball et al., 2000; Hughes, 1992; Burgener & Twigg, 2002; Brod et al., 1999; Ready, Ott, Grace & Fernandez, 2002; Fossey, Lee & Ballard, 2002). It encompasses both positive and negative affect, and life satisfaction (i.e. morale and contentment) (Diener, Suh, Lucas & Smith, 1999; Lawton et al., 1996; Shue, Beck & Lawton, 1996), but most often a selection of these concepts is used for measurement. Instruments for psychological well-being that are used in the elderly are, for instance, the Philadelphia Geriatric Center Morale Scale (PGCMS) (Lawton, 1975) and the Bradburn Affect Balance Scale (Bradburn, 1969). For measuring affect in the elderly, Schulz et al. (1994; in Shue, Beck and Lawton,

1996) recommend the use of, among other scales, the Positive and Negative Affect Scales (Watson, Clark & Tellegen, 1988; Kercher, 1992) and the observational Philadelphia Geriatric Center Positive and Negative Affect Scales (Lawton, Kleban, Dean, Rajagopal, Parmelee, 1992). Both positive affect and negative affect are important dimensions in QOL scales (Noelker, 2002, Brod et al., 1999; Burgener & Twigg, 2002; Ready, Ott, Grace & Fernandez, 2002; Fossey, Lee & Ballard, 2002). Sometimes, however, only negative scales, such as scales for depression, are used in the measurement of QOL (Rabins, Kasper, Kleinman, Black & Patrick, 1999). As the absence of depression does not automatically imply that a resident is happy or content, this poses the question of whether positive and negative scales do, indeed, measure separate constructs and thus, whether or not a negative scale can be used as a single scale for overall QOL.

In this chapter the aim is to investigate the usefulness of six self-report measurement scales for overall QOL (OQOL), by establishing whether they can be administered reliably and validly in a large group of nursing home residents, and whether this is related to cognitive impairment.

1) Which scale(s) can be completed by many residents of different cognitive groups?
2) What is the internal consistency and construct validity of these OQOL scales, and do these properties decrease with cognitive impairment?

We hypothesize that if all scales measure OQOL in nursing home patients validly and reliably, they would correlate highly, within all cognition groups. Moreover, given the assumption of our approach to QOL, i.e. that OQOL results from both physical and social well-being, the scales should not only be related to observational scales that measure OQOL, but also, at least moderately, to observational scales that measure social and physical well-being, in residents with different levels of cognitive impairment. Thus, to investigate construct validity, the following questions are asked:

- How do the respective OQOL scales inter-relate, do these relationships vary for different cognition groups, and are there differences between positive and negative scales?
- To what extent are the OQOL scales related to observational scales for OQOL and social and physical well-being, and does this vary for different cognition groups?

Methods

In the Assess project (more extensively described in Chapter 3), data were collected in nine nursing homes in the Netherlands. The Medical Ethics Committee of the VU University Medical Center had approved the research proposal, and written informed consent was obtained from the participants or their legal

representative. Data were collected on a maximum sample of 30 residents over a period of 3 months per nursing home, with an equal distribution of residents with mainly physical handicaps (in so-called 'somatic' units) and mainly dementia syndromes (in so-called 'psychogeriatric' units).

The data were collected over a total period of 2 years. The principal investigator (DLG, a trained psychologist) administered the self-report QOL scales and the cognitive test (see later), while the nursing staff carried out the observational assessments. The completeness of the interview data depended on the resident's cognitive and physical abilities and willingness to answer questions. The administration of a scale was terminated when a resident proved to be unwilling or unable to respond to the questions that were asked. To assure the validity of cross-sectional comparisons, the self-report and observational scales for each resident were both assessed within the same 4-week period.

Measurement instruments

The scales that were selected to measure QOL had been used before for nursing home residents or frail elderly populations. A distinction was made between scales that ask about QOL literally, scales that focus on positive affect, negative affect or life-satisfaction, and scales that indicate clinical depression.

QOL

A general question on QOL (GEN-QOLQ) was asked: 'Overall, how would you rate the quality of your life at the moment?'. This GEN-QOLQ is part of Brod and co-workers' scale for QOL in people with dementia (Brod et al., 1999) though slightly modified, i.e. 'at the moment' was added, because a pilot study showed that, without this explicit time-limit, the residents tended to evaluate the whole of their past life. The response scale, which is presented in the form of a card, consists of the following response categories: 1 = bad, 2 = moderate, 3 = good, 4 = very good, and 5 = excellent.

The Philadelphia Geriatric Center Morale Scale (PGCMS) (Lawton, 1975) is a self-report scale that has been developed to assess elderly people in institutions, and has been regularly used as an outcome measure in research on QOL and well-being in the elderly (e.g. Yamashita, Iijima, & Kobayashi, 1999; Van Campen & Kerkstra, 1996). It consists of 17 dichotomous items measuring life satisfaction, and the scores are summed, with a high score indicating high QOL. The scale has been found to be reliable, valid and sensitive (Van Campen & Kerkstra, 1996), and internally consistent (KR-20 of .79) (Holtkamp et al., 2000).

The Positive And Negative Affect Scales (PANAS) (Watson, Clark & Tellegen, 1988), were also used. The Positive Affect Scale (PAS) consists of 10 items concerning positive feelings, such as enthusiasm, interest and determination, and the Negative Affect Scale (NAS) consists of 10 items concerning 'negative' feelings,

such as fear, sadness, anxiety and hostility. For this study, the time frame 'today' was chosen, and instead of the original 5-category scale, a 2-category response scale was used, because a pilot study showed that very few residents were able to answer the 5-category scale. The administration was visually mediated, following the procedure proposed for the Depression List (see further). Summing the item-scores yielded two separate total scores, ranging from 0 (no positive/negative affects confirmed) to 10 (all positive/negative affects confirmed). The PAS and the NAS were found to be suitable for use in the elderly (Shue et al., 1996; Kercher, 1992). Earlier reported internal consistency with the time-frame of 'today' yielded a Cronbach's alpha of .90 for the PAS and .87 for the NAS in the general population (Watson, Clark & Tellegen, 1988. The Depression List (DL) is a Dutch self-report screening instrument for depression, especially suitable for the assessment of (elderly) people with dementia (Diesfeldt, 1997). It consists of 15 keywords that are presented on cards, one by one, accompanied by a simple question. For instance, a card with 'down' printed on it is accompanied by the question 'do you feel down?'. Sum-scores range from 0 (no depressive complaints) to 30 (many depressive complaints). In psychometric research, the reported internal consistency of the DL was .82 in a group of visitors to a psychogeriatric day-care clinic (Diesfeldt, 1997), but further psychometric properties have not yet been reported.

The Geriatric Depression Scale (GDS) is a self-report screening instrument for depression in the elderly that is of known reliability and validity, also in long-term care (Brink, Yesavage & Lum, 1982; Kok, 1994). It consists of 30 dichotomous questions, which are summed into total scores, ranging from 0 (no depressive complaints) to 30 (many depressive complaints).

Other scales

The Mini Mental State Examination (MMSE) is a test for cognition, and has scores ranging from 0 (very severe cognitive impairment) to 30 (no cognitive impairment). It is widely used and has been validated, also in long- term care populations (Folstein, Folstein & McHugh, 1975; Kempen, Brilman & Ormel, 1995).

The GIP-sad behavior (Verstraten & Van Eekelen, 1987; Verstraten, 1988) is a sub-scale of the Behavior Observation Scale for Geriatric Inpatients (GIP). The GIP is widely used in nursing homes in the Netherlands, and addresses social, cognitive, psychomotor and emotional 'behavioral types' in elderly residents. It was especially developed for cognitively impaired residents, but is also suitable for physically frail residents (Verstraten, 1988). The 6-item GIP-sad behavior (GIP-S) is used in the present chapter as a scale for QOL, and measures the behavior of elderly people in intramural care settings that expresses sadness, unhappiness, and anxiety. Sum-scores range from 0 (no sad behavior) to 18 (frequent sad

behavior). When first published, the internal consistency (Cronbach's alpha) of the scale was .84, and the inter-rater reliability (Pearson's r) was .74 (Verstraten & Van Eekelen, 1987). In a validation study, internal consistency was found to be .86, and the average inter-rater reliability of the items (Cohen's weighted kappa) was .43, (De Jonghe, Kat & De Reus, 1994). In the present sample, the internal consistency was .81.

The Revised Index for Social Engagement (RISE; see Chapter 4) is an observational instrument to measure social engagement. The RISE is a revision of the Index for Social Engagement (ISE) (Mor et al., 1995). Whereas the ISE rates the resident's ability to take advantage of opportunities for social interaction and to initiate actions that engage her in the daily life of the home, the RISE is more focused on factual interaction and less on the resident's functional ability to engage. It consists of 6 items, four of which are included in the original ISE. The scores range from 0 to 6, with higher values representing more social engagement. The RISE is used in the present study as an indicator of social well-being. Internal consistency in this sample was .73.

The MDS item 'Pain symptoms' measures the frequency with which it is observed that the resident complained or showed evidence of pain in the previous 7 days. It was used in the present study as an indicator of physical well-being. Its response-categories are: no pain; pain less than daily; pain daily.

Analyses

In order to determine whether cognitive status relates to the psychometric properties of the scales, the total group of residents was divided into four MMSE score-groups. An attempt was made to find a division based on known cut-off points that also results in equally large groups. The traditional MMSE cut-off point indicating cognitive impairment is 22/23 (Hartmaier et al., 1995). Among the reported cut-off points for severe cognitive impairment are 16/17 and 17/18 (Kempen et al, 1995), and known cut-off points for reliable self-report assessment are 9/10 (e.g. Brod et al., 1999) and 14/15 (e.g. Mc Givney, 1994). The division into cognition groups was carried out as follows: a MMSE score below 5 (very low cognition group); scores from 5 to 12 (low cognition group); scores from 13 to 21 (moderate cognition group); and scores of 22 or higher ('high' cognition group).

For each MMSE score-group, the number of residents who could complete each scale was calculated, and compared with the number of residents to whom it was offered. Cronbach's alphas were calculated to determine the internal consistency of the scales, and were compared across the different cognition groups. Cronbach's alpha is considered to be fairly good if higher than .70, but should not be higher than .90 (Streiner & Norman, 1995). For construct validity, Spearman coefficients for the interrelationships of the self-report QOL scales were calculated and compared across the different cognition groups. Furthermore,

Spearman coefficients for the relationships of the QOL scales with the observational scales for QOL (GIP-S) and social engagement (RISE), and with the observational question on pain (PAIN) were calculated, and compared across the different cognition groups. Due to the relatively small groups, the correlation coefficients will not be significant below approximately .40. Therefore, all coefficients are described in the results and interpreted as follows: .00 - .10 = no correlation, .11 - .20 = slight correlation, .21- .40 = fair correlation, .41 - .60 = substantial correlation, and .61 - .90 = strong correlation.

Results

Sample description

The overall sample consisted of 227 residents. Their average age was 80.5 (SD 9.26; range 52-100), and 78% were female. The average score on the MMSE (N=200) was 11.8 (SD 9.26); 26.5% had a score below 5, and 18.5% had a score of 22 or higher. The internal consistency of the MMSE in this sample was .89. The curves of the NAS and the DL were slightly positively skewed. The scores on the NAS scales were found to be quite low (Table 1, descriptives total group).

Due to practical considerations and the frailty of the residents, not all scales were administered to all residents. Therefore, the number of completed scales varied, not only because of the inability of some residents to answer the questions, but also because the scales were not offered to all residents.

Table 1. Descriptives and practical utility of self-report QOL scales

	Descriptives			Available MMSE scores	% residents who could complete a scale, per MMSE group1			
	Mean	SD	N	(N)	22-30	13-21	5-12	0-4
GEN-QOLQ (1-5)	2.7	1.0	119	117	97 ($^{35}/_{36}$)	81 ($^{35}/_{43}$)	80 ($^{43}/_{54}$)	11 ($^{4}/_{36}$)
PGCMS (0-17)	10.3	4.5	112	110	94 ($^{34}/_{36}$)	84 ($^{36}/_{43}$)	72 ($^{39}/_{54}$)	3 ($^{1}/_{36}$)
PAS (0-10)	4.4	2.6	102	98	100 ($^{30}/_{30}$)	97 ($^{31}/_{32}$)	94 ($^{34}/_{36}$)	21 ($^{3}/_{14}$)
NAS (0-10)	1.6	1.9	98	94	100 ($^{30}/_{30}$)	97 ($^{30}/_{31}$)	94 ($^{31}/_{33}$)	21 ($^{3}/_{14}$)
DL (0-30)	8.0	5.4	143	135	100 ($^{23}/_{23}$)	96 ($^{26}/_{27}$)	100 ($^{65}/_{65}$)	43 ($^{21}/_{49}$)
GDS (0-30)	10.8	7.0	106	102	100 ($^{37}/_{37}$)	91 ($^{39}/_{43}$)	72 ($^{26}/_{36}$)	0 ($^{0}/_{14}$)

1 Each fraction presents the number of residents who completed the scale in relation to the total number of residents who were offered the scale. Because the scales were not offered to all 227 participants, the numbers in the denominators do not add up to 227, and differ for each scale.

Question 1

Which scale(s) can be completed by many residents of different cognitive groups?

Table 1 reports that in the *high cognition group* (MMSE score of 22 or higher), all six scales could be completed by 94 - 100% of the residents. In the *moderate cognition group* (MMSE score between 13 and 21), all scales, except the GEN-QOLQ and the PGCMS, could be completed by 91 – 97% of the residents. The GEN-QOLQ and the PGCMS could be completed by 84% and 81% in these two groups, respectively. In the *low cognition group* (MMSE score 5-12) the DL still could be completed by all residents (100%), the PAS and the NAS by 94%, the GEN-QOLQ by 80%, and the PGCMS and the GDS by 72%. In the *very low cognition group* (MMSE score below 5) the DL could still be completed by 43% of the residents, but only 21% or less could complete the other scales. The GDS was not completed by any of these residents, and the PGCMS by only 3%.

Question 2

What is the internal consistency and construct validity of the OQOL scales, and do these properties decrease with cognitive impairment?

Only 3 MMSE-groups were used for all further analyses, because in the very low cognition group (n=53) too few residents could complete the scales.

INTERNAL CONSISTENCY: The GEN-QOLQ consisted of one question, so internal consistency analysis was not applicable. Table 2 shows that for the *total group*, Cronbach's alphas were satisfying for all scales, except for the PAS (.55). In the *high cognition group*, the PGCMS, DL and GDS had satisfactory internal consistencies, but those of the PAS and the NAS were below the criterion (.47 and .68, respectively). On the other hand, in the *moderate cognition group*, the alphas of the PAS and the NAS were satisfactory (.77 and .81, respectively), but the alpha of the PGCMS was too low (.53). In the *low cognition group*, the alphas of the scales were satisfactory, although the alpha of the PAS was slightly low (.68).

The internal consistencies of the DL and GDS are therefore satisfactory and those of the NAS are also acceptable, although this scale was somewhat less consistent in the high cognition group. The PGCMS shows good consistency, except in the moderate cognition group. The PAS is the least reliable scale, as it only reaches an acceptable alpha in the moderate cognition group. Further, the scales showed no linear trends of decreasing internal consistency with increasing cognitive impairment, but there were some variations between cognitive groups.

Table 2. Internal consistency (alpha) of OQOL scales for total group, and for MMSE score-groups separately

		Total group		MMSE ≥22 High cognition		MMSE <22 & ≥13 Moderate cognition		MMSE <13 & ≥5 Low cognition	
		Alpha[2] (miic)	N[3]	Alpha (miic)	N	Alpha (miic)	N	Alpha (miic)	N
Positive	PGCMS[1]	.72	108	.81	33	.53	35	.83	38
	(0-17)	(.17)		(.26)		(.14)		(.22)	
	PAS	.55	98	.47	29	.77	30	.68	32
	(0-10)	(.18)		(.20)		(.25)		(.18)	
Negative	NAS	.72	97	.68	29	.81	30	.71	31
	(0-10)	(.18)		(.16)		(.31)		(.17)	
	DL	.81	139	.87	22	.72	26	.79	64
	(0-30)	(.22)		(.30)		(.15)		(.21)	
	GDS	.91	98	.90	34	.92	37	.89	23
	(0-30)	(.24)		(.24)		(.29)		(.22)	

1 As it consists of one question, no alpha coefficient could be calculated for GEN-QOLQ
2 miic = mean inter-item correlation
3 The Ns of the MMSE-groups do not add up to the N of the total group, because some participants (N=27 of N=227) did not have an MMSE-score

CONSTRUCT VALIDITY, INTER-RELATIONSHIP: Table 3 presents the Spearman correlation coefficients for the applied self-report OQOL scales in the three MMSE score-groups. Each correlation coefficient for two scales pertains to all residents who completed both scales. Therefore, the group-sizes differ for the correlation coefficients. Also, the group sizes may be larger than in Table 2, because scale-scores were also calculated when one of the scale's items was missing, using mean substitution. As the results are described for each scale separately, the relationships may be described twice.

The *GEN-QOLQ* correlated fairly or substantially with the DL, GDS and PGCMS, although the strength of the correlation with the PGCMS varied for the cognition groups. The correlation with the PAS and the NAS was absent in the high cognition group. In the other cognition groups the correlation with PAS was fair; the correlation with NAS was fair in the moderate cognition group, and slight, but unexpectedly positive (.13) in the low cognition group. The *PGCMS* correlated strongly with the DL and the GDS in all cognition groups, and it correlated at least substantially with the NAS. Its correlation with the GEN-QOLQ varied for the cognition groups: it was fair in the high and low cognition groups, but strong in the moderate group. The correlation with the PAS was fair. The *PAS* correlated equally fairly in all cognition groups with the PGCMS, DL and GDS. Its correlation with the

Table 3. Correlations between OQOL scales (Spearman's rho), for the MMSE score-groups

	GEN-QOLQ			PGCMS			PAS		
	≥22 HC[1]	<22 ≥13 MC	<13 ≥5 LC	≥22 HC	<22 ≥13 MC	<13 ≥5 LC	≥22 HC	<22 ≥13 MC	<13 ≥5 LC
Positive									
PGCMS	.38*	.61**	.22						
	34	35	37						
PAS	.01	.30	.47**	.19	.21	.34			
	30	30	31	29	31	32			
Negative									
NAS	-.06	-.32	.13	-.51**	-69**	-.47**	-.17	-.10	.16
	30	29	29	29	30	30	30	30	31
DL	-.43*	-.28	-.35*	-.75**	-.79**	-.76**	-.36	-.27	-.25
	23	21	43	23	21	39	19	21	34
GDS	-.47**	-.60**	-.36	-.80**	-.66**	-.65**	-.20	-.43*	-.25
	35	34	24	34	35	25	30	30	23

GEN-QOLQ was absent in the high cognition group, but fair in the moderate and low cognition groups. The positive relationship of PAS with NAS (.16) in the low cognition group was in the unexpected direction, the correlation in the other cognition groups was also slight, though in the right direction. The *NAS* correlated at least substantially with the DL, GDS and PGCMS, and even strongly in the moderate cognition group. Its positive relationship with GEN-QOLQ (.13) and PAS (.16) in the low cognition group was unexpected. The *DL* correlated strongly with the GDS and the PGCMS, substantially with the NAS, and fairly with the GEN-QOLQ and the PAS. The *GDS* correlated strongly with the DL and the PGCMS, at least substantially with the GEN-QOLQ and the NAS, and at least fairly with the PAS.

In summary, the PGCMS, DL and GDS had the strongest relationships. Although they were strong in all cognition groups, especially the relationships of the GDS were clearly lower in the low cognition group. The NAS was substantially correlated with these three. The other relationships between the scales were not very strong. The GEN-QOLQ, PAS and NAS showed some deviations in their relationships with each other. As far as the different cognitive groups are concerned, although the correlations between the scales were mostly lowest in the low cognition group, no clear linear trend across cognition groups was visible. The GEN-QOLQ

separately

NAS			DL		
≥22 HC	<22 ≥13 MC	<13 ≥5 LC	≥22 HC	<22 ≥13 MC	<13 ≥5 LC
.45	.62**	.44*			
19	21	31			
.64**	.65**	.49*	.88**	.77**	
30	29	22	23	20	.69**
					26

1 HC = high cognition group, MC = moderate cognition group, LC = low cognition group

* p<0.05, ** p<0.01

showed relatively large differences between the cognition groups in the strength of the relationships with other scales. The strength of the relationships between the positive PGCMS and the negative NAS, DL and GDS did not indicate any difference in positive and negative constructs.

CONSTRUCT VALIDITY, RELATIONSHIP WITH GIP-S, RISE AND PAIN: The *GEN-QOLQ* correlated fairly with the GIP-S in all cognition groups, with the RISE it correlated fairly in the high cognition group, and with the PAIN it correlated slightly in the high and moderate cognition groups. In the high cognition group, the *PGCMS* correlated fairly with the GIP-S, the RISE and the PAIN. In the moderate cognition group it correlated fairly with the GIP-S and the PAIN. The *PAS* did not correlate with the GIP-S. It correlated fairly with the RISE and the PAIN in the high cognition group, but for the PAIN it was in the wrong direction. In the moderate cognition group the PAS correlated fairly with the PAIN. In the high and moderate cognition groups, the *NAS* correlated fairly or substantially with the GIP-S and the PAIN, but correlated (fairly) in the wrong direction with the PAIN in the low cognition group. With the RISE, the NAS was correlated only (slightly) in the moderate group, but in the wrong direction. In the high and moderate cognition groups, the *DL* correlated fairly or substantially with the GIP-S and the PAIN, it correlated slightly with the

Table 4. Correlations (Spearman's rho) of self report QOL scales with observational meas

	GEN-QOLQ N=119			PGCMS N=112			PAS N=102		
	≥22 HC[1]	<22 ≥13 MC	<13 ≥5 LC	≥22 HC	<22 ≥13 MC	<13 ≥5 LC	≥22 HC	<22 ≥13 MC	<13 ≥5 LC
GIP-S	-.26	-.41*	-.28	-.24	-.40*	-.06	.01	.01	-.08
N=213	35	31	42	34	32	39	30	28	33
RISE	.23	.09	-.04	.31	.02	.00	.24	.10	-.00
N=172	25	26	35	25	27	32	20	22	25
PAIN	-.12	-.16	-.04	-.34	-.22	.01	.15	-.37	-.10
N=205	32	29	40	32	30	36	27	25	31

[1] HC = high cognition group, MC = moderate cognition group, LC = low cognition group
* p<0.05, ** p<0.01

GIP-S in the low cognition group, but correlated (fairly) in the wrong direction with the RISE in the moderate cognition group. In the high cognition group, the *GDS* correlated fairly or substantially with all three scales. This was almost the same in the moderate cognition group, but in the low cognition group it correlated in the wrong direction with the RISE and the PAIN.

Overall, the relationships of the PGCMS, NAS, DL and GDS with the GIP-S and the PAIN were the strongest. They correlated reasonably well in the high and moderate cognition groups. The PGCMS and GDS also correlated fairly with the RISE in the high cognition group, but not in the other cognition groups. The NAS, DL and GDS even had relationships in the wrong direction with the RISE, and the NAS and GDS also had correlations in the wrong direction with the PAIN in the low cognition group. Only two relationships were found in the low cognition group: the GEN-QOL and the DL correlated fairly and slightly, respectively, with the GIP-S.

Discussion

The aim of this chapter was to investigate the usefulness of six self-report scales for measuring overall QOL in nursing home residents. Therefore, it was examined what percentage of residents could complete each scale, how high the internal consistency and construct validity of the scales were, and whether these results were influenced by cognition. It appeared that, of all the scales considered here, the DL could be applied to the most residents, even to almost half (43%) of the residents with very severe cognitive impairment. The other scales could only be applied to a small minority of this group. However, in the higher cognition groups, all scales (except for the PGCMS in the 5-12 MMSE group) could be applied to 80% to 90% of the residents. This percentage is higher than the 60% that was

ures for OQOL (GIP-S), and social (RISE) and physical (PAIN) well-being

NAS N=98			DL N=143			GDS N=106		
≥22 HC	<22 ≥13 MC	<13 ≥5 LC	≥22 HC	<22 ≥13 MC	<13 ≥5 LC	≥22 HC	<22 ≥13 MC	<13 ≥5 LC
.36	.50**	.02	.37	.42*	.14	.39	.43**	.01
30	27	30	23	23	64	37	35	25
-.02	.17	-.09	-.06	.21	-.08	-.34	-.14	.18
20	22	23	18	18	48	27	29	20
.48*	.31	-.31	.39	.25	.00	.47**	.28	-.44
27	25	28	22	22	60	34	33	24

reported by Kane et al. (2003), but refers to shorter scales that only measure OQOL instead of various dimensions of QOL.

In addition to residents being able to complete a scale, the resulting psychometric properties of the scales are of great importance. It appeared that all scales except the PAS had an acceptable internal consistency. Although the alphas varied across the cognition groups, there was no linear trend of decreasing consistency with increasing cognitive impairment. With regard to validity, the PGCMS, DL and GDS (and the NAS to a lesser extent), were strongly correlated in all cognition groups, although overall the correlations in the low cognition group were somewhat lower. These four scales also had the strongest relationships with the scales for OQOL and social and physical well-being. However, these relationships were not strong, especially in the case of the social well-being scale. Moreover, in the low cognition group the scales were not related, or were even related in the wrong direction, to the GIP-S (OQOL), the RISE (social well-being) and the PAIN (physical well-being). This suggests that cognition has a substantial influence on the validity of self-report OQOL-scales.

The PAS performed worst on all aspects. The low internal consistency in the high cognition group could be explained by one item ('determined'). When it was omitted, Cronbach's alpha increased from .52 to .70. Furthermore, its disappointing characteristics can partly be explained by the fact that the PAS measures a somewhat different construct. Its low correlation with the NAS, the other PANAS scale, is not unexpected. Positive and negative affect are considered to be separate entities, and therefore assigned to either the NAS or the PAS (Kercher, 1992). Considering the item content of the five scales, 6 affects (items) of the PAS were not included in the PGCMS, the DL or the GDS (i.e. interested, exited, strong, proud, inspired, and determined), whereas only three affects of the NAS were not

included (i.e. guilty, hostile, and shameful). The PAS therefore must be considered to measures a different construct than the other scales, which also explains the absence of a correlation with the GIP-sad behavior. Although conceptually it may be a good addition to the measurement of OQOL,- as psychological well-being is made up of positive affect, negative affect and life satisfaction -, its poor psychometric performance makes it unsuitable in its present form. In contrast, the other PANAS scale, the NAS, had quite good properties, although the mean score on the NAS was low. The rating of affective states ideally involves a consideration of intensity, duration and frequency (Shue, Beck & Lawton, 1996). However, in cognitively impaired residents it is important to use a self-report scale that is as simple as possible, which may lead to loss of information, and therefore a loss of psychometric quality. For instance, the dichotomized response scale and the time-frame of 'today' that was used for the PAS and the NAS may have resulted in less discriminatory and lower scores, but increasing the response categories and the time-frame would threaten its reliability. We therefore suggest that further research is necessary to investigate the optimal time frame and response categories of the NAS.

Although the DL and the GDS have been developed as screening instruments for depression, they correlated very strongly with the PGCMS, which is a scale for life satisfaction. Studying the item content of the scales, it appeared that the items of these three scales have many similarities. The items of the DL and the GDS contain positive as well as negative affects and also contentment (e.g. 'satisfied', 'happy' and 'hopeful'). Remarkably, although the PCMS is considered to be a positive scale, it has more items that contain negative affects or cognitions (12 out of 17: i.e. 71%) than the GDS (20 out of 30: i.e. 67%), and especially the DL (7 out of 15: i.e. 47%). Therefore, despite the fact that the names of the GDS and the DL suggest a negative scale, they both contain ample positive items. Likewise, the PGCMS cannot be considered to be a solely positive scale. So, each of these scales can be used as a single measure for OQOL, covering both positive and negative aspects.

Considering the large number of residents who were able to complete the DL, and the fact that its psychometric properties are similar to those of the PGCMS and the GDS, it might be concluded that the DL is the most appropriate self-report scale for the measurement of OQOL in nursing home residents. The DL appeared to be reliable in all cognition groups. However, in the low cognition group there was no relationship with the GIP-S, the RISE and the PAIN, indicating poor validity in this group. Therefore, use of the DL in low cognition groups cannot (yet) be recommended.

As in most proxy studies (Novella et al., 2001; Sneeuw et al., 1997; Sneeuw, Aaronson, De Haan & Limburg, 1997), in the present study low correlation was also found between self-report and proxy assessment in low cognition groups

(in this study: observational scales, rated by the nursing staff). This may suggest that the validity of self-report scales decreases with the level of cognition, but also that the validity of observational scales is lower in the low cognition group. Indeed, other research has demonstrated that observational scales become less reliable and valid in low cognition groups, especially those scales that measure a construct that is inherently difficult to observe, such as psychological well-being (see also Chapter 3).

The relationships of the PGCMS, DL and GDS are relatively strong, and the DL and GDS had stable internal consistencies, suggesting that they do provide a fair reflection of how a resident feels. Nevertheless, these scales differ from what is observed by nurses. In our opinion, there are at least two important reasons for this. First, the assessment of a severely cognitively impaired resident may be more dependent on the moment of measurement, even when she is asked to refer to the previous week. A resident who, for instance, regularly experiences pain may, in fact, not be in pain during the administration of the self-report scales, so that the pain may not be taken into consideration. This bias will not be present in observational scales that are assessed by nurses, and suggests that in the measurement of the psychological well-being of cognitively severely impaired residents the time-frame is of extreme importance. Secondly, it may be that residents with dementia have a different experience of their world and the meaning of their experience may very well not be understandable or logical to us. Therefore, it is very possible that standardized observational scales that relate to psychological well-being may not be able to reflect the aspects that are actually relevant for that particular resident. Thus, the absence of a correlation between the two may not be surprising (see also Russell, 1996).

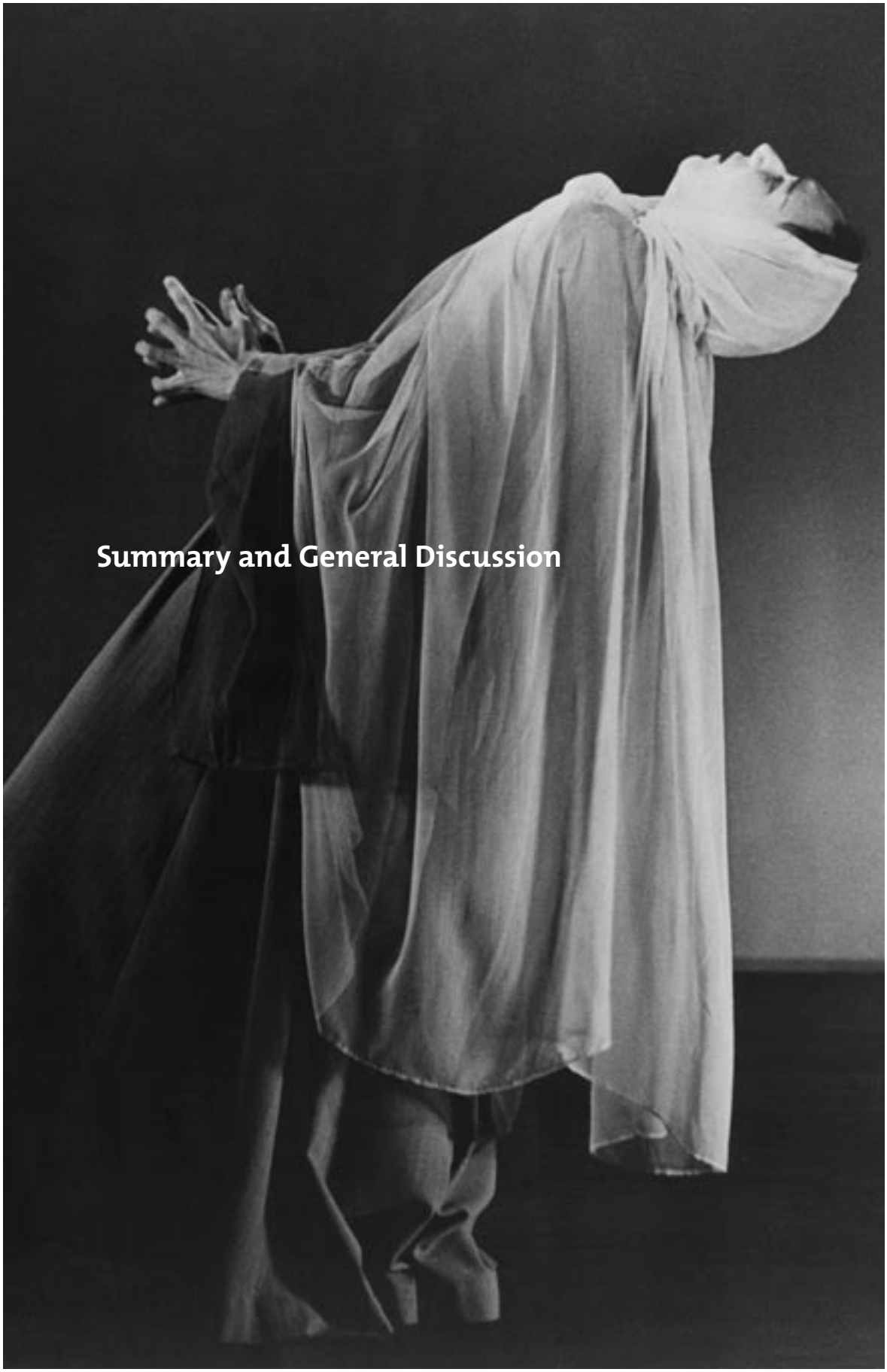
Nevertheless, the self-report and observational scales used to measure QOL (the GIP-S) in the present study were also not strongly correlated in the high cognition groups. In this group, the operationalization of psychological well-being should be adequate. This suggests that, although they are certainly related, self-report and observational scales may measure a different construct, irrespective of the cognitive functioning of the resident. Further research into the relationship of self-report and observational scales for QOL in relation to cognitive performance is therefore highly necessary. This research could use additional positive observational scales for QOL, for instance the Philadelphia Geriatric Center Positive and Negative Affect Scales (Lawton et al., 1992).

The decision as to whether or not a self-report scale can still be administered reliably and validly in a cognitively impaired resident should, in our opinion, be made for individual assessments when administering a QOL-scale. The research on QOL measurement in dementia has shown that one can use screening questions, incorporated in, and thus tailored to the specific cognitive demands of, the scale, in order to determine whether a resident is cognitively able to

answer the questions (Brod et al., 1999). Nevertheless, even if a resident appears to be able to understand the questions, it is not certain that her answers are a true reflection of her inner state. Therefore, further research should focus on developing guidelines on when the administration of a scale can be considered as reliable and valid. This research could, for instance, study the possibility of examining test-retest reliability by repeating questions of a scale throughout the assessment. Such test-retest reliability in the assessment of cognitively impaired residents is an important indication that the resident has understood the questions and that she really communicates her true subjective state. In addition, repeating the assessment on another day and calculating a mean score for the two assessments can result in a more stable self-report QOL score.

This leads to a final consideration about what should be done with variations of QOL assessments over time. As in any human being, QOL can be expected to vary from week to week, from day to day, or even from hour to hour. This may depend on various events that can be important for the resident, such as the onset of pain or a recent family visit. These variations in QOL must be considered as valid by definition. Unfortunately, this complicates the determination of reliability by means of the common test-retest method.

In conclusion, it is very difficult to measure the general and subjective construct that is QOL in the nursing home population through self-report, and possibly also through observation. With regard to observational measures, focusing on specific constructs that are easier to measure, such as cognition, ADL and social engagement will result in more reliable assessments. Nevertheless, self-report will provide valid extra information on the experience of the residents, and is therefore a valuable addition to observational data. The Depression List is a useful scale in this respect, especially for the assessment of groups of nursing home residents with mild to moderate cognitive impairment.



Summary and General Discussion

Chapter 8

Summary and General Discussion

This thesis addresses the quality of life (QOL) of nursing home residents and its measurement. Their QOL is not only important for the residents themselves, but also for researchers, clinicians, nurses, and family members. Of interest are, for instance, the level of QOL that is experienced by the resident, whether it can be improved, how different kinds of care can contribute to QOL, whether it is influenced by family visits, and whether a particular intervention indeed leads to enhanced QOL. However, all these issues can only be addressed if QOL is adequately measured, i.e. when a valid and precise measurement instrument is available. Yet, measurement of the QOL of nursing home residents is a shady field. Firstly, there is still ongoing debate about the exact concept of QOL, and as a consequence there is no consensus on what aspects should be included in an instrument to measure QOL. Secondly, although there is agreement about the fact that the individual concerned is the best source of information, the nursing home resident is generally a very frail elderly person who may not be able to verbally express her QOL, e.g. due to cognitive impairment. Consequently, the objective of this thesis was to find a conceptual approach to QOL that is suitable for use in a nursing home population, and to obtain a means to adequately measure QOL. Despite the preference for self-report, the vantage point for QOL measurement in nursing homes must be observation, because self-report is too difficult for many residents, or will become too difficult during their stay in the nursing home.

An investigation was made of the extent to which the Minimum Data Set (MDS) of the Resident Assessment Instrument (RAI) for nursing homes can be used in the measurement of QOL. The MDS is a comprehensive observational instrument that has been specifically designed to assess long-term care residents, and on the basis of which several measurement scales have been developed. It is the

obvious choice of instrument, because it is being used in many nursing homes worldwide and entails assessment of each resident every three months. However, the psychometric properties of the existing MDS-scales have not yet been extensively tested, and they have not been tested at all in the Netherlands. Moreover, the MDS contains relatively few items on psychosocial well-being, and focuses mainly on problems and deficiencies, an observation that was recently confirmed by Schnelle (2003), Kane et al. (2003) and Holtkamp (2003). Therefore, its usefulness and comprehensiveness for measuring QOL need to be investigated.

In this final chapter the main findings are summarized in an attempt to answer the research questions formulated in the General Introduction. Subsequently, some methodological and conceptual considerations are discussed, followed by the overall conclusions. Finally, the scientific implications and the implications for policy and practice are discussed.

Main findings

The research question that was addressed in Chapter 2 was: are there existing QOL frameworks or approaches that focus on the entire elderly nursing home population and can these be used as a basis for the enhancement of QOL. It was argued that a QOL framework is suitable as a basis for the enhancement of QOL in the nursing home setting if it meets at least three criteria. Only a QOL framework that is (1) based on a comprehensive and universal perspective, (2) illustrates how (sub-)dimensions contribute to QOL and how (sub-)dimensions are inter-related, and (3) is clear about how individual preferences can be represented, can provide the nursing home staff with the necessary tools to decide on how to support the residents in optimizing their QOL. A literature search yielded six QOL frameworks that had been applied to or developed for elderly nursing home residents (or frail elderly people). After a brief discussion and systematic analysis of the six frameworks according to the three criteria, it appeared that the Social Production Functions theory (SPF theory) was the only one that met all three. The basic assumption of the SPF theory is that every individual wants to achieve overall subjective (i.e. psychological) well-being, by realizing physical and social well-being. This is achieved by using one's own preferred resources (i.e. 'things' that one has and does to achieve well-being, for instance food, health care, money, a spouse, cognitive and ADL functioning, or social activities). To a certain extent, these resources are interchangeable. If a certain resource is no longer available, well-being goals can be achieved by using other resources, provided that these are still present, of course. The SPF theory and its applicability in nursing homes are described in detail. It is concluded that this framework seems to be a useful conceptual basis for understanding and measuring the QOL of nursing home residents.

The evaluation of the usefulness of the MDS to measure QOL started with a study of the psychometric properties (i.e. reliability and validity) of the existing MDS-scales. Whereas most studies that focus on these scales use data collected by registered nurses who have been specifically trained for (and employed by) the research project at issue (Gruber-Baldini et al., 2000), in the present study the properties of the MDS scales in daily practice of Dutch nursing homes were investigated. Licensed practical nurses employed by the nursing homes completed the MDS as part of their daily routine (N=227, the 'Assess project').

Chapter 3 describes the investigation of the Activities of Daily Living Self-Performance Hierarchy (ADL-SPH), the Cognitive Performance Scale (CPS) and the Depression Rating Scale (DRS). To determine the intra- and inter-rater reliability of the scales and their items, dual MDS assessments were completed. To determine validity, other measures for the same constructs were assessed, and the relationships between the MDS scales and these 'comparison scales' were studied. The following conclusions were drawn with regard to the quality of the MDS scales. First of all, the ADL-SPH was found to have very high reliability and validity. Secondly, the CPS was found to have good validity and fairly good reliability, i.e. good in residents of somatic units and moderate in residents of psychogeriatric units. Thirdly, with the exception of internal consistency, which was adequate, the reliability of the DRS was found to be moderate, and lower than the reliability of the ADL-SPH and the CPS. This finding is not surprising, because the social and psychological aspects of behavior are known to be more difficult to measure than the functional aspects. Furthermore, the reliability of the DRS was lower in residents of psychogeriatric units than in residents of somatic units. The correlation of the DRS with the sad behavior scale of the Behavior Scale for Psychogeriatric InPatients (GIP-S) and the Geriatric Depression Scale (GDS) in residents with, at the most, moderate cognitive disorders (Mini Mental State Examination (MMSE) $\geq$ 15) is fair. Thus, in this group of residents the DRS can be used as a measure for depressive behavior. In residents with severe cognitive disorders, however, the results are less positive. The correlation of the DRS with the GIP-sad behavior was still moderate, but its weak correlation with the Depression List may point to low validity of the DRS in this group. It is concluded that the ADL-SPH and the CPS appear to be reliable and valid in the measurement of ADL and cognition in nursing home residents, but that the DRS needs to be further investigated with regard to its validity in assessing severely cognitively impaired elderly people.

Chapter 4 describes the investigation of the psychometric properties of the Index for Social Engagement (ISE). To begin with, the definition of the construct of social engagement indicated by the ISE was questioned. Therefore, the literature on the measurement of positive social behavior in the frail elderly was studied. Thirteen scales were found, and twenty clinical experts were asked to rate the importance of the dimensions that were represented in these scales. It appeared

that two very relevant dimensions of social engagement, both concerning factual interactions with other people, were not represented in the ISE. Therefore, two new items were formulated: 'initiates interaction with others', and 'responds positively to interactions initiated by others'. Furthermore, it appeared that two items that were included in the ISE might not be relevant for social engagement. This was confirmed by internal consistency analyses of data from Dutch and Canadian nursing homes, which led to the proposal of a new version of the scale: the Revised Index for Social Engagement (RISE), in which two existing ISE items were omitted and the two new items were added. Compared with the original ISE, the RISE has higher internal consistency, inter-rater reliability, and construct validity, which are most pronounced in residents with severe cognitive problems. It is concluded that the RISE should replace the ISE in the MDS.

The evaluation of the usefulness of the MDS to measure QOL was continued by studying the possibility of constructing a new scale based on psychosocial MDS items. In Chapter 5 the aim was to construct a reliable and valid behavioral scale for challenging behavior. Based on the SPF theory, challenging behavior can be linked to the (social) well-being of the resident. This link may improve the understanding and the management of such behavior by the nursing staff and other caregivers. Five clinical experts selected MDS items concerning resident behavior that may evoke reactions such as irritation, frustration and/or rejection from the (nursing) staff, other residents and/or visitors. This would, according to the SPF theory, undermine their willingness to fulfill the resident's needs (i.e. goals) with regard to well-being. Exploratory factor analyses of a sample of 656 nursing home residents yielded a 15-item scale, the Challenging Behavior Profile (CBP), that contains four internally consistent and valid sub-scales, measuring conflict behavior, withdrawn behavior, restless and repetitive behavior, and claiming behavior. This could largely be confirmed using data from the Assess project, and it is concluded that the CBP may be an important contribution to the existing clinical MDS scales.

Chapter 6 describes the construction of a reliable and valid positive observational scale for social well-being. A scale based on new (non-MDS) items was constructed as an addition to the MDS. This made it possible to measure more items that are relevant for QOL, according to the SPF theory. Firstly, items were formulated and tested for intra- and inter-rater reliability in a sample of 308 nursing home residents. The results show that a 9-item scale for social well-being could be constructed to assess the dimensions of affection, behavioral confirmation and status, according to 3 strong 3-item sub-scales. Analyses of psychometric properties, using data from the Assess project, showed that the scale and its sub-scales had modest to good reliability and validity. These results suggest that this scale,

the scale for Social Well-being Of Nursing home residents (SWON), is a valuable addition to the MDS in the assessment of nursing home residents. It measures certain aspects of social well-being that are considered to be important in daily nursing home life, but have, until now, not received consistent attention.

Chapter 7 concerns the exploration of the usefulness of self-report scales for overall QOL for nursing home residents with various degrees of cognitive impairment. It was investigated which proportion of the residents of varying degrees of cognitive impairment could complete a scale, and the internal consistency and construct validity of the scales was analyzed. Six self-report scales for overall QOL were selected to be compared using data from the Assess project. It appeared that the validity of most scales is lower in groups with low cognition. The Depression List could be administered most often to the cognitively most impaired group. Together with the GDS, it also had the best psychometric properties. Nonetheless, self-report scales did not appear to be strongly correlated with observational scales for overall, social and physical well-being, and not at all in cognitively severely impaired residents, which raises questions about their validity. Before drawing conclusions with regard to the usefulness of self-report scales, it is necessary to study the reproducibility of these self-report measures.

Methodological considerations

This thesis is based on data from three separate data sets. This created the opportunity to validate the constructed scales on independent samples. The sample of the Assess project was used as a validation sample in the empirical studies described in Chapters 3 to 7. For the construction of the Challenging Behavior Profile (Chapter 5), an additional sample was used, providing MDS data on 656 residents of somatic and psychogeriatric units in three Dutch nursing homes. These nursing homes belong to the 'Verenigde Amstelhuizen' (VA) corporation in Amsterdam, which started an ambitious project to implement the RAI instrument correctly in September 2002, after it had been using the RAI haphazardly for several years. The data in this 'VA data-set' were collected according to the instructions in the RAI Manual (Frijters, 2001). In addition, for the construction of the SWON scale (Chapter 6), use was made of data that had been collected for the 'Benchmarking in long-term care' project (Frijters, Gerritsen & Steverink, 2003). This provided data on 308 residents in three Dutch nursing homes. Both the VA data-set and the 'Benchmarking data-set' are briefly described in the relevant chapters. Since the data from the Assess project are used most extensively in this thesis, these data and their consequences for the results of the study are discussed in more detail. The psychometric properties that were studied are also described, followed by a discussion on the generalizability of the results.

The Assess project data-set

The aim of the Assess project was to investigate the reliability and validity of MDS scales *as they are used in clinical practice*. The psychometric properties reported by those who developed the scales in the United States are almost all based on assessments made by registered nurses who have been specifically trained for research purposes (Gruber-Baldini et al., 2000). In daily nursing home practice, however, the licensed practical nurses who provide daily care complete the MDS. This may lead to different results with regard to the properties of the scales. Therefore, for the purpose of the study, MDS data were collected as in daily practice, which may have had some effects on the results.

Firstly, to limit the involvement of the nursing staff as much as possible to MDS assessments, it was decided to use self-report scales for validity, if feasible, and to use a maximum of one observational scale per MDS scale. The principal investigator (DLG) administered the self-report scales, whereas the nursing staff administered the observational scales. This may have introduced some bias, for it can be expected that an observational scale will correlate more with another observational scale of the same construct than with a self-report scale. This may have led to an underestimation of the properties of the MDS scales. Furthermore, observational scales pertain to the entire population, whereas self-report scales often cannot be administered to severely (cognitively) impaired residents, which complicated the interpretation of the properties of scales.

Secondly, the study could only enroll nursing homes that worked with the RAI. At the time, only 10 out of the 340 nursing homes in the Netherlands worked with the RAI, and 9 of these participated in the study. This might have caused selection bias. It appears that the basic demographic characteristics of the Assess sample are approximately the same as those of residents in the other nursing homes in the Netherlands (Prismant & Arcares, 2002). The mean age in the Assess sample was 79.9 (77.3 for residents of somatic units; 82.6 for residents of psychogeriatric units), and for residents in all nursing homes in the Netherlands at that time it was 80.6 (and 77.6 and 82.7 respectively). The percentage of women was 78 in the Assess-sample, and 72.3 in all Dutch nursing homes. However, the representativeness of the results will probably not be threatened by differences in age or gender, but may well be threatened by an under-representation of specific levels of cognitive or ADL functioning. Nevertheless, the (normal) distribution and ranges of the scores on the pertaining scales suggest that all measurable levels were represented. Moreover, a differentiation was made between residents of somatic and psychogeriatric units and between different degrees of cognitive impairment, which provided information on the usefulness of the scales in specific groups of residents. In the paragraph 'Applicability of the results to specific groups and patients' this issue is further described.

The results may also have been influenced more than expected by the 'daily practice-aim' of the study-design, because it appeared that the RAI was often poorly implemented. Contrary to the instructions in the RAI Manual, MDS assessments were often done less than quarterly, and the information that had been gathered was often not actually applied in the care process. The assessors had all received training in the MDS protocol, but nonetheless there was great variation in their experience with MDS assessments. Moreover, the MDS assessment planning of a unit was subject to considerable change, and as a result, many MDS assessments were late and some were even omitted. Consequently, the time-interval between the assessments often exceeded one month (range of time-interval: 5 – 67 days). This incomplete and qualitatively low implementation of the RAI may have led to an under-estimation of the properties of the scales under better circumstances.

In conclusion, the approach to data-collection for the MDS scales, as they were applied in clinical practice, may have led to an under-estimation of the actual properties of the scales. This, although regrettable, is less detrimental than a possible over-estimation.

Psychometric properties

Although the terms reliability and validity are familiar to most researchers, the pertaining terminology in the literature is diverse, especially for validity (e.g. content validity, criterion validity, concurrent validity, predictive validity, construct validity, convergent validity and discriminant validity). Some of these types of validity are hard to distinguish and are sometimes used inconsistently. In this thesis, validity testing was mainly about construct validity. Construct validity refers to the various methods used to determine whether a scale is able to tap a particular construct, of which convergent validity was most applied. Convergent validity can be tested by correlating a new scale to an existing scale measuring a similar construct, or by testing the correlation with a scale measuring a construct to which it is theoretically related (see Appendix 4 for a description of the types of reliability and validity studied in this thesis). To strengthen this approach, most scales were validated against more than one comparison scale or by several hypotheses. However, a complicating factor was that few of the scales that are commonly used in the Netherlands have actually been validated in Dutch nursing home populations. As a result weak relationships between scales are difficult to interpret, because it may not be the scale under study that is invalid, but the comparison scale. Further psychometric research in Dutch nursing homes is therefore strongly recommended.

A drawback of this study is that criterion validity could not be investigated. The use of golden standards (diagnostic instruments) would have made it possible to study sensitivity and specificity, but such an approach would have

been much too labor-intensive and costly for this broad investigation. However, further research based on diagnostic interviews as gold standard, is highly recommended, and this does not only apply to the Netherlands, but also to all other countries in which the MDS scales are used.

Responsiveness to change, an important aspect of the usefulness of scales to monitor residents over time, is not reported. Although follow-up assessments had, indeed, been carried out (for residents of somatic units after 6 months, and for residents of psychogeriatric units after 12 months), it appeared that too few of the residents who were still in the nursing home had changed, so that it was not possible to determine responsiveness. Further research in a larger sample, with a longer time-interval is necessary, but it will always be a problem to find clinically relevant indicators of change and to cope methodologically with the enormous drop-out due to disease and death.

Applicability of the results to specific groups and patients

The validity of the results of this study is dependent on inherent scale properties and the characteristics of the population it is tested on, and the quality of the data collection. This thesis describes the results in long-stay residents from 9 homes working with RAI and 3 additional homes, which may have led to selection-bias. But selection was also part of the design. In particular, small groups of residents, e.g. those that had been admitted for short-stay, were excluded on purpose. The reason for this is that the nursing home population is a highly heterogeneous and changing population, and one may question the value of 'average' results. Rather, the characteristics of (groups of) residents that may influence the properties of the scales are of higher importance. Therefore, an attempt was made to select a restricted sample that represented the various characteristics of long-term nursing home residents (albeit without strict in- or exclusion criteria), but which was subsequently stratified for psychogeriatric and somatic units or for different degrees of cognitive impairment. Thus, valid results for more homogenous populations could be obtained. Nonetheless, this stratification is probably not sufficient to cover the great heterogeneity of the nursing home population. The limited sample size prevented further stratification, and one can not exclude that other relevant characteristics may not have been recognized. Yet, conclusions with regard to the psychometric properties of the scales have been drawn for specific groups, which contributes to their usefulness in daily practice.

It should be mentioned that the MDS is also considered to be appropriate for use in residential homes (Morris et al., 1990). However, it is possible that it is more difficult for nurses in residential homes to assess the residents through observation. Obviously, they interact less frequently and in fewer circumstances, so that they (have to) rely more on self-reports of the residents. This may influence

the psychometric properties of the scales, given the above-mentioned difference between self-report and observational data. Therefore, additional research into the psychometric properties of these scales in residential homes is recommended.

Conceptual considerations

The basic assumption that is made in this thesis is that insight into the dimensions of QOL and their inter-relationship provides information on how QOL can be improved, and is a prerequisite for the effectiveness of care. In this thesis, the basic assumptions of the SPF theory appeared to be most suitable to provide this insight. Therefore, this theory was used as the main starting point for determining the usefulness of the MDS to measure QOL. It confirmed the suggested need for the development of additional instruments to measure social well-being, and has guided the development of the scales for challenging behavior and social well-being. Nevertheless, there are some considerations with regard to the SPF theory that need additional attention.

It is an assumption of the SPF theory that every individual has an intrinsic motive to gain well-being. However, it can be questioned whether severely cognitively impaired residents still have this intrinsic motive, and whether and how they use their resources. The common symptom of 'impaired goal-directed behavior' may make it more difficult for the residents to fulfill their needs for well-being. Yet, on the other hand, they may have adjusted to the situation by lowering the amount of resources that is necessary to fulfill a need. An example is the question how the QOL dimension of 'stimulation' applies to residents with impaired goal-directed behavior. A study carried out by Gerritsen, Jongenelis, Steverink, Ooms & Ribbe (in press) suggests that less stimulation was needed by those residents, because it was found that cognitively impaired residents may express high levels of QOL when they show apathetic behavior, whereas cognitively intact residents will express low levels of QOL when they show apathetic behavior.

The main focus of this thesis was on social and psychological (i.e. overall) well-being, because these aspects are under-exposed in the MDS. For the same reason, the Centers for Medicare and Medicaid Services (CMS) in the United States, who commissioned the development of the MDS, funded a study to be carried out by Kane et al. (2003) to develop QOL scales that reflect psychosocial domains that were omitted from, or not directly emphasized in the MDS. As other researchers in the field of nursing home care (Van Campen & Kerkstra, 1998; Ball et al., 2000), they also attach much importance to *safety* and *autonomy* as dimensions of QOL in nursing home residents, dimensions that are not included in the SPF hierarchy presented in this thesis.

According to the SPF theory, safety and autonomy pertain to another category of goals, the meta-goals (in addition to the substantial goals of stimulation, comfort, affection, behavioral confirmation and status). Meta-goals fall beyond the scope of this thesis and reference is made to Van Bruggen (2001) for a detailed description. Yet, the dimensions (i.e. meta-goals) of safety and autonomy will be briefly discussed here.

According to the SPF theory, feeling safe means that the ways for gaining well-being are perceived as stable (Lindenberg, 1996; Steverink, 1996). Feeling unsafe is a signal that the resident's usual ways to gain well-being are disrupted, for instance because she has lost a very important resource for well-being (e.g. the use of her legs), and that she has become dysfunctionally preoccupied with this loss. A resident who has slipped into this 'loss-perspective' will not be able to find new ways of gaining well-being, and will feel unsafe. When care-providers help her to find new priorities and strengths, stability can be restored and the theory predicts that she will feel safe again.

The dimension of autonomy is important in approaches to QOL in nursing home residents because the specific context of the nursing home may pose threats to the resident's sense of self-direction, freedom of choice and perceived control. In terms of the meta-goals in the SPF theory, having the freedom to act and being in control provides opportunities for the efficient gaining of well-being. It is a regretful fact that autonomy is not self-evident in the nursing home environment, and that this environment may even interfere with gaining well-being instead of contributing to it. Of course, the condition of many nursing home residents, especially those with dementia, may be a reason for the nursing staff to prevent or intervene in certain behavior, and they sometimes do, indeed, 'know what is best for the resident'. However, this should only happen in the case of behavior that is harmful to the resident herself and/or people in her environment. Autonomy, as a dimension in the approaches to QOL in nursing home residents, is not a question of preventing harm, but refers to the extent to which an institution (and its care-providers) values its residents and provides client oriented and demand-driven care that aims to secure the resident's sense of autonomy. In such an environment the resident will be more effective in achieving her well-being goals.

Although the SPF approach appears to be very promising, and the results from this study have not raised questions about its applicability, it should be systematically tested empirically in a sample of nursing home residents. This research should incorporate the above-mentioned conceptual considerations and the dimensions for physical well-being. It could focus on the possible influence of severe cognitive impairment on the relationships between psychological, physical and social well-being, and the sub-dimensions of comfort, stimulation,

affection, behavioral confirmation and status. Moreover, the hierarchy of meta-goals, which includes safety and autonomy, could also be a focus of study.

Conclusion

The following can be concluded with regard to the goals of this thesis, i.e. to find a conceptual *approach to quality of life* that is suitable for use in nursing homes and, on the basis of that approach, to obtain a means for adequate *measurement of quality of life*.

An approach to QOL was found, which provided information as to what should be measured. To estimate the level of QOL, the three dimensions of social well-being and the two dimensions of physical well-being in this approach should be measured, and scales for psychological well-being can be used to obtain information on overall QOL. To effectively optimize QOL it is also necessary to obtain information about the individual's resources and preferences. According to the SPF-theory, residents can be expected to have great difficulty in recuperating from the losses they are so often confronted with. They must (repeatedly) adjust to a new situation with more limitations than before (Steverink, 2001). In order to adapt to the new situation, the resident's preferences have to be redirected, and in this respect, it is highly important that the nursing staff focuses on the remaining strengths and potentials, and assists the resident by maintaining these strengths. Although the RAI primarily focuses on problems and disabilities, the MDS can provide important information about a resident's resources by considering the information from another perspective, i.e. the remaining resources. For instance, it can provide information on the absence of pain, the absence of diseases, intact cognitive and ADL functioning, the resident's social activities and social interaction. For two of these resources, valid measurement scales are already available: the CPS and the ADL-SPH (Chapter 3). The CBP, which was developed in this study (Chapter 5), can be considered as a 'contra-resource' of (social) well-being that will influence the extent to which the resident's well-being needs are fulfilled.

The MDS provides fewer possibilities to obtain insight into well-being. The DRS can be used as an outcome measure, but it is necessary to improve its psychometric properties, especially in the case of low cognition. The RISE measures social engagement, which is a prerequisite for social well-being (Chapter 4). In general, social engagement, and thus the scores on the RISE, will strongly relate to social well-being. However, to measure social well-being according to the SPF theory it is important to measure its three dimensions, and therefore the SWON was developed (Chapter 6). To measure physical well-being, which is not addressed in this thesis, further research is necessary. The MDS contains many items relating to physical aspects, and the possibility of using the MDS to measure the physical well-being dimensions of 'comfort' and 'stimulation' should be studied.

Thus, the MDS can definitely be used by care-providers aimed at the enhancement of QOL, but may not yet be equipped well enough to date to measure the level of well-being of nursing home residents. In this study it was found that more than 80% of the residents were able to provide a self-report based on simple scales for overall QOL, with relatively little loss of internal consistency. The Depression List could even be administered reliably in 43% of the residents with an MMSE-score below 5. The validity of these self-report scales has not yet been fully tested (Chapter 7). The scores of the self-report scales correlated at most moderately with the scores of the observational scales. Apparently, self-report and observational scales measure something different. In addition to further testing of the validity of self-report measures, the development of adequate observational instruments to measure physical well-being and improvement of the DRS to measure overall well-being would be a worthwhile focus of further research.

Scientific implications

When further research confirms the usefulness of the SPF theory and the scales that have been developed, they can form the basis for guidelines to enhance the QOL of nursing home residents. The SPF theory provides a rationale for the relationship between QOL and quality of care, and further research should focus on that link. Because most residents have lost many resources to achieve QOL goals, they are very dependent on the nursing home staff for the enhancement of their QOL. As follows from the SPF theory, optimal contribution to QOL is not only the best possible fulfilling of the resident's care needs. It is also a fulfilling of her physical and social well-being goals using her strengths and abilities, helping her to redirect her goals when resources are lost (to prevent her from feeling unsafe), and thereby letting her determine her own ways of gaining well-being (autonomy). To make an effective contribution, it is necessary to know which goals are the most important for the resident and how she would prefer them to be fulfilled (individual preferences). The resident's possible inability to express or even determine what she feels is really important, must be a special point of interest in this research, in the development of guidelines, and in the implementation of interventions to enhance QOL. The next step is to develop and evaluate guidelines for the enhancement of QOL on the basis of the SPF theory. If the nurses understand how their own behavior can contribute to the QOL of the residents, individually tailored interventions can be developed and effectively applied in the care-planning.

Implications for policy and practice

Whereas the results concerning the MDS scales for ADL and cognition were satisfactory, the scores of cognitively impaired residents on the DRS should be interpreted with caution. As a rule of thumb, this applies to residents with a

score equal to or higher than 2 on the CPS, the MDS scale for cognition. All three scales have already been incorporated in the RAI software that is used in the Netherlands. This thesis shows that the RISE and the CBP also deserve a place in the RAI software. The SWON, which is not a MDS scale, provides supplementary information on well-being that adds to the MDS information, and the possibility of incorporating the SWON in the RAI-MDS should also be investigated.

This thesis stresses the importance of addressing the psychosocial aspects of life in a nursing home and of a client-oriented approach. Although these concepts have been discussed in the literature for decades, the under-representation of these aspects in a relatively recently developed instrument such as the RAI illustrates that the focus in nursing home care often is still very much on physical care needs and problems. However, the view that the RAI is problem-oriented mainly stems from the use of the MDS to screen for potential problems, and a corresponding problem-analysis protocol (RAP). The MDS items can, on the other hand, also be used to create a 'profile of strengths' that focuses on the remaining resources of a resident. This profile could help to prevent residents from institutionalization and from being considered as a problematic case. The MDS scales that have been developed so far can also be used in (multidisciplinary) consultations to draw attention to psychosocial aspects. By formally incorporating the wishes and preferences of the resident into the care-planning, client-tailored care can be stimulated. Although the RAI does not formally ensure a client-oriented approach, it can be integrated, for instance by using the 'Care-chart' (in Dutch: 'Zorgkaart'), which has actually been incorporated in the Dutch version of the RAI software. The Care-chart is a 2-sided one-page form containing the MDS items that are most important for providing ADL-care. Client-oriented care is thus enhanced, because the nurses have to indicate for every item how the resident wants the care to be provided.

The MDS appeared not to cover all relevant aspects for the measurement of QOL. Nevertheless, it is an important means to chart the resources that a resident has to achieve well-being. This, in combination with additional information on the residents' preferences, can be applied in client-tailored interventions, and can also be used to evaluate these interventions. In addition to the current profile of risks, a profile of strengths should be developed for RAI.

Until recently, the RAI did not have a positive reception in the Netherlands. This study, the study carried out by Holtkamp (2003) and the Verenigde Amstelhuizen RAI-implementation project (which started in the autumn of 2002) have shown that the implementation of the RAI in nursing homes in the Netherlands had been incomplete. Institutions need to integrate the RAI into their existing care-planning procedures. This means that a nursing home has to be willing to throw its familiar procedures and methodology overboard, and incorporate the RAI in every aspect of its care process (e.g. admission, formulation of the care-

plan, meetings, evaluation of the care-plan) and management strategies. Now that the Verenigde Amstelhuizen are re-implementing the RAI, it has become clear that the RAI can really be an asset to the care that is provided, but before it can be considered beneficial it must generate information on the status of the residents that is both useful and practical for nursing staff and management. Combined with interventions to enhance QOL based on the residents' strengths and preferences, it can contribute to realizing client-oriented care that targets QOL.

References

Achterberg, I., Kok, W., & Salentijn, C. (1997). 'Snoezelen', a new way of communicating with the severely demented elderly. In G. M. M. Jones & B. M. L. Miesen (Eds.), *Caregiving in dementia, Volume 2.* London / New York: Routledge.

Achterberg, W., Pot, A. M., Kerkstra, A., Ooms, M. E., Muller, M., & Ribbe, M. W. (2003). The effect of depression on social engagement in newly admitted Dutch nursing home residents. *The Gerontologist, 43,* 213-218.

Albert, S. M. (1997). Assessing Health-Related Quality of Life in Chronic Care Populations. *Journal of Mental Health and Aging, 3*, 111-118.

Albrecht, G. L., & De Vlieger, P. J. (1999). The disability paradox: High quality of life against all odds. *Social Science and Medicine, 48,* 977-988.

Allen-Burge, R., Stevens, A. B., & Burgio, L. D. (1999). Effective behavioral interventions for decreasing dementia-related challenging behavior in nursing homes. *International Journal of Geriatric Psychiatry, 14*, 213-228.

Anderson, R. L., Buckwalter, K. C., Buchanan, R. J., Maas, M. L., & Imhof, S. L. (2003). Validity and reliability of the Minimum Data Set Depression Rating Scale (MDSDRS) for older adults in nursing homes. *Age & Ageing, 32,* 435-438.

Angermeyer, M. C. & Kilian, R. (1999). Theoretical Models of Quality of Life for Mental Disorders. In H. Katschnig, H. Freeman, & N. Sartorius (Eds.), *Quality of Life in Mental Disorders.* Chichester: John Wiley & sons.

Auer, S. R., Monteiro, I. M., & Reisberg, B. (1996). The Empirical Behavioral Pathology in Alzheimer's Disease (E-BEHAVE-AD) Rating Scale. *International Psychogeriatrics, 8,* 247-266.

Ball, M. M., Whittington, F. J., Perkins, M. M., Patterson, V. L., Hollingworth, C., King, S. V., & Combs, B. L. (2000). Quality of life in assisted living facilities: Viewpoints of residents. *Journal of Applied Gerontology, 19,* 304-325.

Bassuk, S. S., Glass, Th. A., & Berkman, L. F. (1999). Social disengagement and incident cognitive decline in community-dwelling elderly persons. *Annals of Internal Medicine, 131,* 165-173.

Baum C., Edwards, D. F., & Morrow-Howell, N. (1993). Identification and measurement of productive behaviors in senile Dementia of the Alzheimer type. *The Gerontologist, 33*, 403-408.

Beck. C., Frank, L., Chumbler, N. R., O'Sullivan, P., Vogelpohl, T. S., Rasin, J., Walls, R., & Baldwin, B. (1998). Correlates of disruptive behavior in severely cognitively impaired nursing home residents. *The Gerontologist, 38,*189-198.

Bellelli, G., Frisoni, G. B., Bianchetti, A., & Trabucchi, M. (1997). The Bedford Alzheimer Nursing Severity scale for the severely demented: validation study. *Alzheimer Disease and Associated Disorders, 11,* 71-77.

Bennett, K. M. (2002). Low level social engagement as a precursor of mortality among people in later life. *Age and Ageing, 31,* 165-168.

Birren, J. E., Lubben, J. E., Rowe, J. C., & Deutchman, D. E. (Eds.). (1991). *The concept and measurement of quality of life in the frail elderly.* San Diego, Academic Press.

Bliwise, D. L., & Lee, K. A. (1993). Development of an Agitated Behavior Rating Scale for discrete temporal observations. *Journal of Nursing Measurement,* 1,115-124.

Bradburn, N. M. (1969). Two dimensions of psychological well-being: Positive and negative affect. In N. M. Bradburn & C. E. Hill (Eds.), *The structure of psychological well-being.* (pp. 53-70). Chicago: Aldine Publishing Co.

Brink, T. L., Yesavage, J. A., Lum, O., Heersema, P. H., Adey, M., & Rose, T. L. (1982). Screening tests for geriatric depression. *Clinical Gerontologist, 1,* 37-43.

Brod, M., Stewart, A. L., Sands, L., & Walton, P. (1999). Conceptualization and measurement of quality of life in dementia: the dementia quality of life instrument (DQOL). *The Gerontologist, 39,* 25-35.

Brod, M., Stewart, A. L., & Sands, L. (1999). Conceptualization of quality of life in dementia. *Mental Health and Aging, 5,* 7-19.

Brown, I., Renwick, R., & Nagler, M. (1996). The centrality of quality of life in health promotion and rehabilitation. In: R. Renwick, I. Brown, & M. Nagler (Eds.), *Quality of life in health promotion and rehabilitation: Conceptual approaches, issues, and applications.* Thousand Oaks: Sage Publications, Inc.

Burgener, S., & Twigg, P. (2002). Relationships among caregiver factors and quality of life in care recipients with irreversible dementia. *Alzheimer Disease and Associated Disorders, 16,* 88-102.

Burrows, A. B., Morris, J. N., Simon, S. E., Hirdes, J. P., & Phillips, C. (2000). Development of a minimum data set-based depression rating scale for use in nursing homes. *Age and Ageing, 29,* 165-172.

Cohen, J. (1960). A coefficient of agreement for nominal scales. *Educational and Psychological Measurement, 20,* 37-46.

Cohen, J. (1968). Weighted kappa: Nominal scale agreement provision for scaled disagreement or partial credit. *Psychological Bulletin, 70,* 213-220.

Cohen-Mansfield, J. & Billig, N. (1986). Agitated behaviors in the elderly: I. A conceptual review. *Journal of the American Geriatrics Society, 34,* 711- 721.

Cohen-Mansfield, J. (2001). Nonpharmacologic interventions for inappropriate behaviors in dementia: A review, summary, and critique. *American Journal of Geriatric Psychiatry, 9,* 361-381.

Cohen-Mansfield, J. (2003). Nonpharmacologic Interventions for Psychotic Symptoms in Dementia. *Journal of Geriatric Psychiatry and Neurology, 16,* 219-224.

Cronbach, L. J. (1951). Coefficient alpha and the internal structure of tests. *Psychometrika, 16,* 297-334.

Cummings, J. L. (1997). The Neuropsychiatric Inventory: assessing psychopathology in dementia patients. *Neurology, 48,* S10-S16.

Cummings, J. L., Mega, M., Gray, K., Rosenberg-Thompson, S., Carusi, D. A., & Gornbein, J. (1994). The Neuropsychiatric Inventory: comprehensive assessment of psychopathology in dementia. *Neurology, 44,* 2308-2314.

De Jonghe, J. F. M., Kat, M. G., & De Reus, R. (1994). De validiteit van de Gedragsobservatieschaal voor de Intramurale Psychogeriatrie (GIP): een vergelijking met de BOP en NOSIE-30 in een psychiatrische observatiekliniek voor ouderen. [Validity of the Behavior Observation Scale for Intramural Psychogeriatrics: a comparison with the BOP (Evaluation Scale Elderly Patients) and NOSIE-30 in a psychogeriatric assessment clinic for the elderly]. *Tijdschrift voor Gerontologie en Geriatrie, 25,* 110-116.

Diener, E., Suh, E. M., Lucas, R. E., & Smith, H. L. (1999). Subjective well-being: Three decades of progress. *Psychological Bulletin, 125,* 276-302.

Diesfeldt, H. F. A. (1997). De Depressielijst: Een instrument voor stemmingsonderzoek in de psychogeriatrie. [A depression inventory for psychogeriatric patients]. *Tijdschrift voor Gerontologie en Geriatrie,* 28,113-118.

Diesfeldt, H. F. A. (1996). *De Depressielijst voor stemmingsonderzoek in de psychogeriatrie.* [The Depression list for mood-research in psychogeriatrics]. Laren NH, Psychogeriatrische Dienst, report nr. 96.13.

Dittmar, S. S., & Gresham, G. E. (1997). *Functional assessment and outcome measures for the rehabilitation health professional.* Gaithersburg, Aspen Publishers.

Drachman, D. A., Swearer, J. M., O'Donnell, B. F., Mitchell, A. L., & Maloon, A. (1992). The Caretaker Obstreperous-Behavior Rating Assessment (COBRA) Scale. *Journal of the American Geriatrics Society, 40,* 463-70.

Dröes, R. M. (1991). *In beweging: over psychosociale hulpverlening aan demente ouderen.* Utrecht, De Tijdstroom.

Duine, T. J. (1991). De validiteit van een nieuwe psychogeriatrische gedragsobservatieschaal (OPG) voor toepassing in verpleeg- en verzorgingstehuizen. [The validity of a new psychogeriatric rating scale (OPG) in nursing homes and homes for the aged.] *Tijdschrift voor Gerontologie en Geriatrie, 22,* 228-233.

Erikson, E. H., Erikson, J. M., & Kivnick, H. (1986). *Vital involvement in old age.* New York: W. W. Norton & Company.

Farina, A., Arenberg, D., & Guskin, S. (1957). A scale for measuring minimal social behavior. *Journal of Consulting Psychology, 21,* 265-268.

Faulk, L. E. (1988). Quality of life factors in board and care homes for the elderly: A hierarchical model. *Adult Foster Care Journal, 2,* 100-117.
Feil, N. (1989). Validation, an empathic approach to the care of dementia. *Clinical Gerontologist, 8,* 89-94.
Feil, N. (1992). Validation therapy with late-onset dementia populations. In G. M. M. Jones & B. M. L. Miesen (Eds.), *Caregiving in dementia, Research and applications.* London / New York: Routledge.
Fernandez-Ballesteros, R. (1995). Quality of life: Concept and assessment. In J. Georgas, M. Manthouli, E. Besevegis, & A. Kokkevi (Eds.), *Contemporary Psychology in Europe: Theory, Research, and Applications.* Hogrefe & Huber Publishers: Seattle.
Ferrans, C. E. (1996). Development of a conceptual model of quality of life. *Scholarly Inquiry for Nursing Practice, 10,* 293-304.
Finkel, S. I., Lyons, J. S., & Anderson, R. L. (1993). A brief agitation rating scale (BARS) for nursing home elderly. *Journal of the American Geriatrics Society, 41,* 50-52.
Finkel, S. I. (2002). Behavioral and psychological symptoms of dementia: Assisting the caregiver and managing the patient. *Geriatrics, 57,* 44-46.
Finnema, E. J., Dröes, R. M., Ribbe, M. W., & van Tilburg, W. (2000). The effects of emotion oriented approaches in the care for persons suffering from dementia: A review of the literature. *International Journal of Geriatric Psychiatry, 15,* 141-161.
Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). Mini-mental state: A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research, 12,* 189-198.
Fortinsky, R. H., Granger, C. V., & Seltzer, G. B. (1981). The use of functional assessment in understanding home care needs. *Medical Care, 19,* 489-497.
Fossey, J., Lee, L., & Ballard, C. (2002). Dementia Care Mapping as a research tool for measuring quality of life in care settings: Psychometric properties. *International Journal of Geriatric Psychiatry, 17,* 1064-1070.
Frederiksen, K., Tariot, P., & De Jonghe, E. (1996). Minimum Data Set plus (MDS+) scores compared with scores from five rating scales. *Journal of the American Geriatrics Society, 44,* 305-309.
Frijters, D. (1996). *Gebruikershandboek patiëntbeoordelingsinstrument RAI voor instellingen met langdurige zorg.* Utrecht: SIG Zorginformatie.
Frijters, D., Achterberg, W., Hirdes, J. P., Fries, B. E., Morris, J. N., & Steel, K. (2001). Geïntegreerd gezondheidsinformatiesysteem op basis van Resident Assessment Instrumenten [Integrated health information system based on Resident Assessment Instruments]. *Tijdschrift voor Gerontologie en Geriatrie, 32,* 8-16.
Frijters, D., Gerritsen, D., & Steverink, N. (2003). Zorginhoudelijke kwaliteit, betrouwbaarheid en bruikbaarheid van observatiegegevens in de benchmark

voor verpleeg- en verzorgingshuizen. [Care quality, reliability and usefulness of observation data in bench marking nursing homes and homes for the aged in the Netherlands.] *Tijdschrift voor Gerontologie en Geriatrie, 34,* 21-29.

Gauthier, S., Baumgarten, M., & Becker, R. (1996). Dementia Behavior Disturbance Scale. *International Psychogeriatrics, 8(Suppl 3),* 325-327.

George, L. K., & Bearon, L. B. (1980). *Quality of Life in Older Persons: Meaning and Measurement.* New York: Human Sciences Press.

Gerritsen, D. L., Jongenelis, K., Steverink, N., Ooms, M. E., & Ribbe, M. W. (in press). Down & Drowsy? Do apathetic nursing home residents experience low quality of life? *Aging and Mental Health.*

Gilbart, E. E., & Hirdes, J. P. (2000). Stress, social engagement and psychological well-being in institutional settings: Evidence based on the Minimum Data Set 2.0. *Canadian Journal on Aging, 19 (Suppl2),* 50-66.

Goode, D. A., & Hogg, J. (1994). Towards an understanding of holistic quality of life in people with profound intellectual and multiple disabilities. In D. A. Goode (Ed.), *Quality of life for persons with disabilities, International perspectives and issues.* Cambridge (US): Brookline Books.

Gorissen, J. P. (1986). Een differentiële beschrijving van de SDAT-patiënt met twee gedragsobservatieschalen, de BOP en de GOS-G. [A differential description of the SDAT-patient with the BOP and the GOS-S.] *Tijdschrift voor Gerontologie en Geriatrie, 17,* 17-24.

Green, S., & Cooper, B. A. (2000). Occupation as a quality of life constituent: A nursing home perspective. *British Journal of Occupational Therapy, 63,* 17-24.

Gruber-Baldini, A. L. , Zimmerman, S. I., Mortimore, E., & Magaziner, J. J. (2000). The validity of the minimum data set in measuring the cognitive impairment of persons admitted to nursing homes. *Journal of the American Geriatrics Society, 48,* 1601-1606.

Gurland, B., & Katz, S. (1997). Quality of Life and Mental Disorders of Elders. In H. Katschnig, H. Freeman, & N. Sartorius (Eds.), *Quality of life in mental disorders.* New York: John Wiley & Sons.

Hartmaier, S. L., Sloane, P. D., Guess, H. A., Koch, G. G., Mitchell, C. M., & Phillips, C. D. (1995). Validation of the Minimum Data Set Cognitive Performance Scale: agreement with the Mini-Mental State Examination. *Journal of Gerontology: Medical Sciences, 50,* M128-M133.

Harvey, P. D., Davidson, M., Mueser, K. T., Parrella, M., White, L., & Powchik, P. (1997). Social Adaptive Functioning Evaluation (SAFE): A rating scale for geriatric psychiatric patients. *Schizophrenia Bulletin,* 23, 131-145.

Hawes, C., Morris, J. N., Phillips, C. D., Mor, V., Fries, B. E. & Nonemaker, S. (1995). Reliability estimates for the Minimum Data Set for nursing home resident assessment and care screening (MDS). *The Gerontologist, 35,* 172-178.

Helmes, E., Csapo, K. G., & Short, J. (1987). Standardization and validation of the Multidimensional Observation Scale for Elderly Subjects (MOSES). *Journal of Gerontology, 42,* 395-405.

Hirdes, J. P., Frijters, D. H., & Teare, G. F. (2003). The MDS-CHESS Scale: A New Measure to Predict Mortality in the Institutionalized Elderly. *Journal of the American Geriatric Society, 51,* 96-100.

Holtkamp, C. C. M. (2003). *Effects of the Resident Assessment Instrument on quality of care and quality of life in nursing homes.* Utrecht: Nivel.

Holtkamp, C. C., Kerkstra, A., Ribbe, M. W., Van Campen, C., & Ooms, M.E. (2000). The relation between quality of co-ordination of nursing care and quality of life in Dutch nursing homes. *Journal of Advanced Nursing, 32,* 1364-1373.

Honigfeld, G., Gillis, R. D., & Klett, C. J. (1966). NOSIE-30: a treatment-sensitive ward behavior scale. *Psychological Reports, 19,* 180-182.

Hughes B. (1990). Quality of Life. In S. M. Peace (Ed.), *Researching Social Gerontology, concepts, methods and issues*. London: SAGE.

Jette, A. M., Davies, A. R., Cleary, P. D., Calkins, D. R., Rubenstein, L. V., Fink, A., Kosecoff, J. Young, R. T., Brook, R. H., & Delbanco, T. L. (1986). The Functional Status Questionnaire: reliability and validity when used in primary care. *Journal of General Internal Medicine, 1,* 143-149.

Kane, R. A. (2001). Long-term care and a good quality of life: bringing them closer together. *The Gerontologist, 41,* 293-304.

Kane, R. A. (2003). Definition, measurement, and correlates of quality of life in nursing homes: toward a reasonable practice, research, and policy agenda. *The Gerontologist, 43 (Special Issue 2),* 28-36.

Kane, R. A., Kling, K. C., Bershadsky, B., Kane, R. L., Giles, K., Degenholtz, H. B., Liu, J., & Cutler, L. J. (2003). Quality of life measures for nursing home residents. *Journal of Gerontology: Medical Sciences, 58,* M240-M248.

Katz, S., & Gurland, B. J. (1991). Science of Quality of life in elders: Challenge and Opportunity. In J. E. Birren, J. E. Lubben, J. C. Rowe, & D. E. Deutchman (Eds.), *The concept and measurement of quality of life in the frail elderly.* San Diego: Academic Press.

Kempen G. I., Brilman E. I. , & Ormel J. (1995). De Mini-Mental State Examination. Normeringsgegevens en een vergelijking van een 12- en 20-item versie in een steekproef ouderen uit de bevolking. [The Mini Mental Status Examination. Normative data and a comparison of a 12-item and 20-item version in a sample survey of community-based elderly]. *Tijdschrift voor Gerontologie en Geriatrie, 26,* 163-172.

Kempen, G. I. J. M., Brilman, E. I., & Ormel, J. (1998). Groningen Longitudinal Aging Study: Een onderzoek naar het dagelijks functioneren, het welbevinden en de zorgbehoefte van ouderen. [The Groningen Longitudinal Aging Study (GLAS)

on functional status, well-being and need of care: Objectives, design and preliminary results]. *Tijdschrift voor Gerontologie en Geriatrie, 29,* 141-149.
Kercher, K. (1992). Assessing subjective well-being in the old-old: The PANAS as a measure of orthogonal dimensions of positive and negative affect. *Research on Aging, 14,* 131-168.
Kiely, D. K., Simon, S. E., Jones, R. N., & Morris, J. N. (2000). The protective effect of social engagement on mortality in long-term care. *Journal of the American Geriatric Society, 48*, 1367-1372.
Kivnick, H. Q. (1993). Everyday mental health: A guide to assessing life strengths. *Generations, 17,* 13-20.
Kok, R. M. (1994). Zelfbeoordelingsschalen voor depressie bij ouderen. [Self-evaluation scales for depression in the elderly]. *Tijdschrift voor Gerontologie en Geriatrie, 25,* 150-156.
Landis, J. R., & Koch, G. C. (1975). A review of statistical methods in the analysis of data arising from observer reliability studies (Part I). *Statistica Neerlandica, 29,* 101-123.
Lawlor, B. (2002). Managing behavioural and psychological symptoms in dementia. *British Journal of Psychiatry,181,* 463-465.
Lawton, M. P. (1975). The Philadelphia Geriatric Center Morale Scale, a revision. *Journal of Gerontology, 30*, 85-89.
Lawton, M. P. (1983). Environment and other determinants of well-being in older people. *The Gerontologist, 4,* 349-357.
Lawton, M. P. (1991). A Multidimensional View of Quality of Life in Frail Elders. In J. E. Birren, J. E. Lubben, J. C. Rowe, & D. E. Deutchman (Eds.), *Quality of Life in the Frail Elderly.* San Diego: Academic Press Inc..
Lawton, M. P. (1994). Quality of Life in Alzheimer Disease. *Alzheimer Disease and Associated Disorders, 8 (Suppl 3),* 138-150.
Lawton, M. P. (1997). Assessing quality of life in Alzheimer disease research. *Alzheimer Disease and Associated Disorders, 11(suppl. 6),* 91-99.
Lawton, M. P., Kleban, M. H., Dean, J., Rajagopal, D., & Parmelee, P. A. (1992). The factorial generality of brief positive and negative affect measures. *Journal of Gerontology: Psychological Sciences, 47,* P228-P237.
Lawton, M. P., Van Haitsma, K., & Klapper, J. (1996). Observed affect in nursing home residents with Alzheimer's disease. *Journal of Gerontology: Psychological Sciences, 51,* P3-P14.
Lindenberg, S. (2001). Social rationality versus rational egoism. In J. H. Turner (Ed.), *Handbook of Sociological Theory.* New York: Kluwer Academic / Plenum Publishers.
Lindenberg, S. (1986). The paradox of privatization in consumption. In A. Diekman, & P. Mitter (Eds.), *Paradoxical Effects of Social Behavior.* Heidelberg / Wien: Physica-Verlag.

Lindenberg, S. (1996). Continuities in the theory of social production functions. In H. Ganzeboom, & S. Lindenberg (Eds), *Verklarende sociologie, opstellen voor Reinhard Wippler* [Explanatory sociology, essays for Reinhard Wippler] (pp. 169-184). Amsterdam, Thesis Publishers.

Liseno, E. M., & Kennedy, J. L. (1975). Measuring changes in the level of functioning of severely impaired geriatric patients. *Massachusetts Journal of Mental Health, 5,* 18-29.

Logsdon, R. G., & Albert, S. M. (1999). Assessing quality of life in Alzheimer's disease: Conceptual and methodological issues. *Journal of Mental Health and Aging, 5,* 3-6.

Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (1999). Quality of life in Alzheimer´s disease: patient and caregiver reports. *Journal of Mental Health and Aging, 5,* 21-32.

Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri L. (2002). Assessing quality of life in older adults with cognitive impairment. *Psychosomatic Medicine, 64,* 510-519.

Mahoney, E. K. Volicer, L. & Hurley A. C. (1999). *Management of Challenging Behaviors in Dementia*. Baltimore, Health Professions Press.

Mahoney, F. I., & Barthel, D. W. (1965). Functional evaluation: *The Barthel Index. Maryland State Medical Journal, 14*, 61-65.

Maslow, A. H. (1970). *Motivation and personality* (2nd edition). New York: Harper & Row.

Maslow, A. H. (1968). *Toward a psychology of being* (2nd edition). New York: Van Nostrand Reinhold.

McAdams, D. P. (1994). *The Person: An introduction to personality psychology* (2nd edition). Orlando: Harcourt Brace & Company.

McGivney, S. A., Mulvihill, M., & Taylor, B (1994). Validating the GDS depression screen in the nursing home. *Journal of the American Geriatrics Society, 42,* 490-492.

Molloy, D. W., Bedard, M., Guyatt, G. H., & Lever, J. (1996). Dysfunctional Behavior Rating Instrument. *International Psychogeriatrics, 8 (Suppl 3),* 333-341.

Montgomery, A. A., Graham, A., Evans, P. H., & Fahey, T. (2002). Inter-rater agreement in the scoring of abstracts submitted to a primary care research conference. *BMC Health Services Research 2002, 2,* 8.

Mor, V., Branco, K., Fleishman, J., Hawes, C., Philips, C., Morris, J., & Fries, B. (1995). The Structure of Social Engagement Among Nursing Home Residents. *Journal of Gerontology: Psychological Sciences, 50*, P1-P8.

Morris, J. N., Fries, B. E., & Morris, S. A. (1999). Scaling ADL's Within the MDS. *Journal of Gerontology: Medical Sciences, 54,* M546-M553.

Morris, J. N., Fries, B. E., Mehr, D. R., Hawes, C., Philips, C., Mor, V., & Lipsitz, L. A. (1994). MDS Cognitive Performance Scale. *Journal of Gerontology: Medical Sciences, 49,* M174-M182.

Morris, J. N., Hawes, C., Fries, B. E., Phillips, C. D., Mor, V., Katz, S., Murphy, K., Drugovich, M. L., & Friedlob, A. S. (1990). Designing the national resident assessment instrument for nursing homes. *The Gerontologist, 30,* 293-307.

Morris, J. N., Murphy, K., & Nonemaker, S. (1995). *Long Term Care Resident Assessment Instrument User's Manual Version 2.0.* Baltimore, Health Care Financing Administration.

Mozley, C. G., Huxley, P., Sutcliffe, C., Bagley, H., Burns, A., Challis, D., & Cordingley, L. (1999). 'Not knowing where I am doesn't mean I don't know what I like', cognitive impairment and quality of life responses in elderly people. *International Journal of Geriatric Psychiatry, 14,* 776-783.

Nieboer A. P. (1997). *Life events and well-being: a prospective study on changes in well-being of elderly people due to a serious illness event or death of the spouse.* Amsterdam, Thesis Publishers.

Noelker, L. (2002). Overview and Conceptual Approaches to Quality of Life and Dementia Quality of Life. *The Gerontologist, 42* (special issue II), 400.

Novella, J. L., Jochum, C., Jolly, D., Morrone, I., Ankri, J., Bureau, F., & Blanchard, F. (2001). Agreement between patients' and proxies' reports of quality of life in Alzheimer's patients. *Quality of Life Research 2001,* 10, 443-452.

Ormel, J., Lindenberg, S., Steverink, N., & Verbrugge, L. (1999). Subjective well-being and social production functions. *Social Indicators Research, 46,* 61-90.

Ormel, J., Lindenberg, S., Steverink, N., & Vonkorff, M. (1997). Quality of Life and Social Production Functions: A Framework for Understanding Health Effects. *Social Science and Medicine, 45,* 1051-1063.

Patrick, D. L., & Erickson, P. (1993). *Health status and health policy: quality of life in health care evaluation and resource allocation.* New York: Oxford University Press.

Peavy, G. M., Salmon, D. P., Rice, V. A., Galasko, D., Samuel, W., Taylor, K. I., Ernesto, C., Butters, N., & Thal, L. (1996). Neuropsychological assessment of severely demented elderly, the severe cognitive impairment profile. *Archives of Neurology, 53,* 367-372.

Prismant & Arcares (2002). *Verpleeghuizen in cijfers 2000: informatie van LZV en SIVIS.* [Nursing homes by numbers 2000: information from LZV and SIVIS]. Utrecht: Prismant/Arcares.

Rabins, P. V., Kasper, J. D., Kleinman, L., Black, B. S., & Patrick, D.L. (1999). Concepts and methods in the development of the ADRQL: an instrument for assessing health-related quality of life in persons with Alzheimer´s disease. *Mental Health and Aging 1999, 5,* 33-48.

Rabins, P.V., & Kasper, J.D. (1997). Measuring quality of life in dementia: conceptual and practical issues. *Alzheimer Disease and Associated Disorders, 11 (Suppl 6),* 100-104.

Raphael, D., Brown, I., Renwick, R., & Rootman, I. (1997). Quality of Life: What Are the Implications for Health Promotion? *American Journal of Health Behavior, 21,* 118-128.

Ray, W. A., Taylor, J. A., Lichtenstein, M. J., & Meador, K. G. (1992). The Nursing Home Behavior Problem Scale. *Journal of Gerontology: Medical Sciences, 47,* M9-M16.

Ready, R. E., & Ott, B. R. (2003). Quality of Life measures for dementia. *Health and Quality of Life Outcomes, 1,* 11.

Ready, R. E., Ott, B. R., Grace, J., & Fernandez, I. (2002). The Cornell-Brown scale for quality of life in dementia. *Alzheimer's Disease and Associated Disorders, 16,* 109-115.

Reisberg, B., Auer, S. R., & Monteiro, I. M. (1996). Behavioral pathology in Alzheimer's disease (BEHAVE-AD) rating scale. *International Psychogeriatrics, 8 (Suppl 3),* 301-308.

Ribbe, M. W. (1993). Care for the Elderly: the role of the nursing home in the Dutch health care system. *International Psychogeriatrics, 5,* 213-222.

Ribbe, M. W., Ljunggren, G., Steel, K., Topinkova, E., Hawes, C., Ikegami, N., Henrard, J. C., & Jonnson, P. V. (1997). Nursing homes in 10 nations, a comparison between countries and settings. *Age and Ageing, 26* (S2), 3-12.

Rosen, J., Burgio, L., Kollar, M., Cain, M., Allision, M., Fogleman, M., Michael, M., & Zubenko, G. (1994). The Pittsburgh Agitation Scale, A user-friendly instrument for rating agitation in dementia patients. *American Journal of Geriatric Psychiatry, 2,* 52-59.

Rossaert I. (1989). Reminiscentie, leven en werken met herinneringen. *Tijdschrift voor Gerontologie en Geriatrie, 20,* 167-168.

Russell, C. K. (1996). Passion and heretics: Meaning in life and quality of life of persons with dementia. *Journal of the American Geriatrics Society, 44,* 1400-1402.

Saxton, J., McGonigle-Gibson, K. L., Swihart, A. A., Miller, M., & Boller, F. (1990). Assessment of the severely impaired patient: Description and validation of a new neuropsychological test battery. *Psychological Assessment, 2,* 298-303.

Scheibel, A. B., Morgan, D. G., Grady, C. L., Rapoport, S. I., Gurland, B., & Katz, S. (1992). Neuroscience and aging. In J. E. Birren, R. B. Sloane, G. D. Cohen, N. R. Hooyman, B. D. Lebowitz, M. H. Wykle, & D. E. Deutchman (Eds.), *Handbook of mental health and aging* (2nd ed.). San Diego, Academic Press, 1992, 147-248.

Schnelle, J. F. (2003). Improving nursing home quality assessment: capturing the voice of cognitively impaired elders. *Journal of Gerontology: Medical Sciences, 58,* M238-M239.

Selai, C., & Trimble, M. R. (1999). Assessing quality of life in dementia. *Aging and Mental Health 3,* 101-111.

Selai, C. E., Trimble, M. R., Rossor, M. N., & Harvey, R. J. (2001). Assessing quality of life in dementia: Preliminary psychometric testing of the Quality of Life Assessment Schedule (QOLAS). *Neuropsychological Rehabilitation, 11,* 219-243.

Sgadari, A., Morris, J. N., Fries, B. E., Ljunggren, G., Jonsson, P.V., DuPaquier, J. N., & Schroll, M. (1997). Efforts to establish the reliability of the RAI. *Age and Ageing, 26(S2)*, 27-30.

Shrout, P. E. & Fleiss, J. L. (1979). Intraclass correlations: Uses in assessing rater reliability. *Psychological Bulletin, 86,* 420-428.

Shue, V., Beck. C., Lawton, M. P. (1996) Measuring affect in frail and cognitively impaired elders. *Journal of Mental Health and Aging, 2,* 259-271.

Shye, S. (1989). The systemic life quality model: A basis for urban renewal evaluation. *Social Indicators Research, 21,* 343-378.

Sinha, D., Zemlan, F. P., Nelson, S., Bienenfeld, D., Thienhaus, O., Ramaswamy, G., & Hamilton, S. (1992). A new scale for assessing behavioral agitation in dementia. *Psychiatry Research, 41,* 73-88.

Sneeuw, K. C., Aaronson, N. K., De Haan, R. J., & Limburg, M. (1997). Assessing quality of life after stroke: The value and limitations of proxy ratings. *Stroke, 28,* 1541-1549.

Sneeuw, K. C., Aaronson, N. K., Osoba, D., Muller, M. J., Hsu, M. A., Yung, W. K., Brada, M., & Newlands, E. S. (1997). The use of significant others as proxy raters of the quality of life of patients with brain cancer. *Medical Care, 35,* 490-506.

Sneeuw, K. C., Sprangers, M. A., & Aaronson, N. K. (2002). The role of health care providers and significant others in evaluating the quality of life of patients with chronic disease. *Journal of Clinical Epidemiology, 55,* 1130-1143.

Snowden, M., McCormick, W., Russo, J., Srebnik, D., Comtois, K., Bowen, J., Teri, L., & Larson, E. B. (1999). Validity and responsiveness of the Minimum Data Set. *Journal of the American Geriatrics Society, 47,* 1000-1004.

Snowden, M., Sato, K., & Roy-Byrne, P. (2003). Assessment and treatment of nursing home residents with depression or behavioral symptoms associated with dementia, a review of the literature. *Journal of the American Geriatrics Society, 51,* 1305-1317.

Spiegel, R., Brunner, C., Phil, L., Ermini-Fuenfschilling, D., Monsch, A., Notter, M., Puxty, J., & Tremmel, L. (1991). A new behavioral assessment scale for geriatric out- and in-patients, The NOSGER (Nurses' Observation Scale for Geriatric Patients). *Journal of the American Geriatrics Society, 39,* 339-347.

Steverink, N. (1995). *Zo lang mogelijk zelfstandig. Naar een verklaring van verschillen in oriëntatie ten aanzien van opname in een verzorgingstehuis onder fysiek kwetsbare ouderen.* Amsterdam: Thesis Publishers.

Steverink, N. (2001). When and why frail elderly people give up independent living: The Netherlands as an example. *Aging and Society, 21,* 45-69.

Steverink, N., Lindenberg, S., & Ormel, J. (1998). Towards understanding successful ageing: patterned change in resources and goals. *Aging and Society, 18,* 441-467.

Stewart, A. L. & King, A. C. (1994). Conceptualizing and measuring quality of life in older populations. In R. P. Abeles, H. C. Gift, & M. G. Ory (Eds.), *Aging and quality of life. Springer series on life styles and issues in aging*. New York: Springer Publishing.

Streiner, D. L., & Norman, G. R. (1995). *Health measurement scales: a practical guide to their development and use* (2nd ed.). New York: Oxford University Press.

Tariot, P. N., Mack, J. L., Patterson, M. B., Edland, S. D., Weiner, M. F., Fillenbaum, G., Blazina, L., Teri, L., Rubin, E., Mortimer J. A., et al. (1995). The Behavior Rating Scale for Dementia of the Consortium to Establish a Registry for Alzheimer's Disease. The Behavioral Pathology Committee of the Consortium to Establish a Registry for Alzheimer's Disease. *American Journal of Psychiatry, 152,* 1349-57.

Teri, L., & Logsdon, R. G. (1991). Identifying pleasant activities for Alzheimer's disease patients: The Pleasant Events Schedule-AD. *The Gerontologist, 31,* 124-127.

Tractenberg, R. E., Gamst, A., Weiner, M. F., Koss, E., Thomas, R. G., Teri, L., & Thal, L. (2001). Frequency of behavioral symptoms characterizes agitation in Alzheimer's disease. *International Journal of Geriatric Psychiatry, 16,* 886-891.

Tyne, A. (1985). Measuring Quality of Life in residential services for mentally handicapped people. In A. Robertson, & A. Osborn (Eds), *Planning to care: Social policy and the quality of life*. Aldershot (England): Gower Publishing Company.

Van Bruggen, A. (2001). *Individual production of social wellbeing, An Exploratory Study*. Amsterdam, Thela Thesis.

Van Campen, C, & Kerkstra, A. (1996). Ervaren kwaliteit van leven van somatische verpleeghuispatienten: een overzicht van meetinstrumenten. [Experienced quality of life of somatic nursing home patients, a review of measuring instruments]. *Tijdschrift voor Gerontologie en Geriatrie, 27,* 20-28.

Van Campen, C., & Kerkstra, A. (1998). Ervaren kwaliteit van leven van somatische verpleeghuispatienten: een overzicht van meetinstrumenten. De constructie van een meetinstrument. [Perceived quality of life of elderly somatic nursing-home patients. Construction of a measuring instrument] *Tijdschrift voor Gerontologie en Geriatrie, 29,* 11-18.

Van Eijk, L. (1997). *Activity and Well-being in the Elderly.* Amsterdam: Thesis Publishers.

Van der Steen, J. T., Ooms, M. E., Van der Wal, G., & Ribbe, M. W. (2002). Pneumonia, the demented patient's best friend? Discomfort after starting or withholding antibiotic treatment. *Journal of the American Geriatrics Society, 50,*1681-1688.

Van Nieuwenhuizen, C., Schene, A. H. & Koeter, M. W. J. (2001). Quality of life in forensic psychiatry: An unreclaimed territory? *International Review of Psychiatry, 14,* 198-202.

Verstraten, P. F. (1988). The GIP, an observational ward behavior scale. *Psychopharmacology Bulletin, 24*, 717-719.

Verstraten, P. F. J., & Van Eekelen, C. W. J. M. (1987). *Handleiding voor de GIP, Gedragsobservatieschaal voor de Intramurale Psychogeriatrie.* [GIP Manual, Behavior Observation Scale for Geriatric Inpatients.] Deventer, Van Loghum Slaterus.

Volicer, L., & Bloom, C. L. (1999). *Enhancing the quality of life in advanced dementia.* Philadelphia: Brunner/Mazel Inc..

Volicer, L., Hurley, A. C., Lathi, D. C., & Kowall, N. W. (1994). Measurement of severity in advanced Alzheimer's disease. *Journal of Gerontology: Medical Sciences, 49,* M223-M226.

Watson, D., Clark, L., & Tellegen, A. (1988). Development and validation of brief measures of positive and negative affect: The PANAS scales. *Journal of Personality & Social Psychology, 54,* 1063-1070.

Whitehouse, P. (1999). Quality of Life in Alzheimer's Disease: Future Directions. *Journal of Mental Health and Aging, 5,* 107-111.

Whitehouse, P. & Maslow, K. (1997). Defining and measuring outcomes in Alzheimer disease research: introduction and overview. *Alzheimer Disease and Associated Disorders, 11 (Suppl 6),* 1-6.

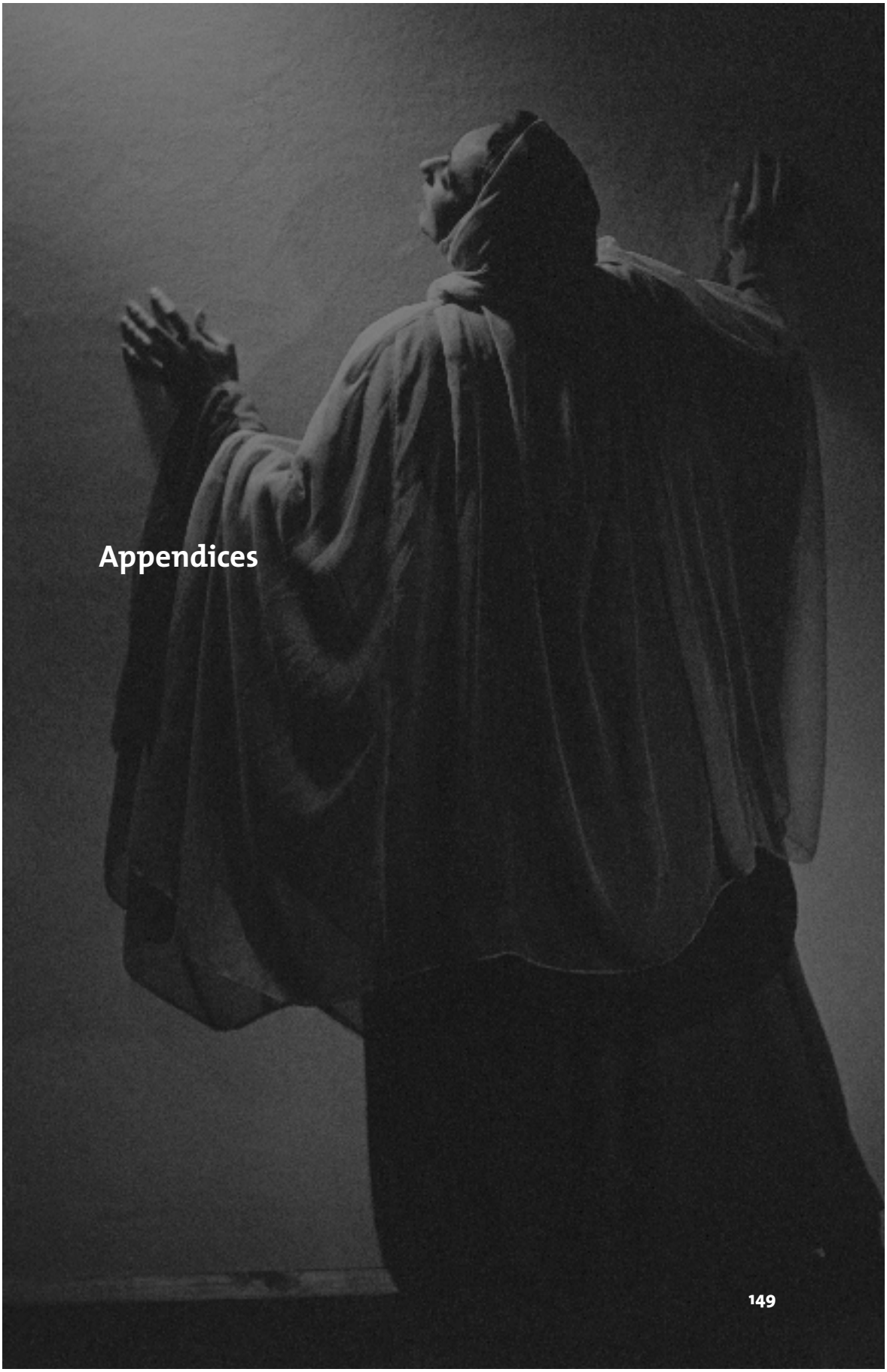
Whitehouse, P J. & Rabins, P. V. (1992). *Quality of life and dementia. Alzheimer Disease and Associated Disorders, 6,* 135-137.

Wilson, I. B., & Cleary, P. D. (1995). Linking clinical variables with health-related quality of life: A conceptual model of patient outcomes. *Journal of the American Medical Association,* 273, 59-65.

Yamashita, K., Iijima, K., & Kobayashi, S. (1999). Relationship among activities of daily living, apathy, and subjective well-being in elderly people living alone in a rural town. *Gerontology, 45,* 279-282.

Zautra A, & Goodhart D. (1979). Quality of life indicators, a review of literature. *Community Mental Health Review, 4,* 1-10.

Zijp, E. M., Van den Bosch, J. S., & Van Hezik, S. (1995). Geriatrische revalidatie in een verpleeghuis en de Barthel-index als graadmeter. [Geriatric rehabilitation in a nursing home and the Barthel Index as a parameter]. *Nederlands Tijdschrift voor Geneeskunde, 139,*1037-1041.



Appendices

Appendix 1. Minimum Data Set

Identificatienummer _____

MINIMUM DATA SET (MDS) — *VERSIE 2.0*

VOOR BEOORDELING EN ZORGBEPALING VAN VERPLEEGHUISPATIËNTEN

SECTIE AA. IDENTIFICATIE-INFORMATIE (***Moet altijd worden ingevuld*** **)**

1.	NAAM PATIËNT	a. (Voornaam) b. (Initialen) c. (Achternaam)
2.	GESLACHT	1. Man 2. Vrouw
3.	GEBOORTE-DATUM	Dag — Maand — Jaar
5.	ZORGVER-ZEKERAAR EN POLISNR	a. Verzekeraar: _____ b. Polisnummer:
6.	CODE VERPLEEG-HUIS	
7.	IDENTIFICA-TIE	a. Uniek identificatienummer: b. Kamernummer: c. Afdelingsnummer:
8.	REDENEN VOOR BEOORDE-LING	a. Belangrijkste reden voor beoordeling 1. Beoordeling bij eerste opname (moet op dag 14 zijn uitgevoerd) 2. Jaarlijkse beoordeling 3. Beoordeling vanwege een wezenlijke toestandsverandering 4. Wezenlijke correctie van een eerdere beoordeling 5. Kwartaalbeoordeling (*apart formulier voor Secties A t/m R*) 6. Ontslag—geen heropname voorzien 7. Ontslag—heropname voorzien 8. Ontslag voordat de eerste beoordeling klaar was 9. Heropname 0. GEEN VAN BOVENSTAANDE b. Speciale codes voor wanneer om een of andere reden op een afwijkend tijdstip een volledige beoordeling wordt uitgevoerd 1. 5-de dag beoordeling 2. 30-ste dag beoordeling 3. 60-ste dag beoordeling 4. Kwartaalbeoordeling met invulling van volledig MDS 5. Heropnamebeoordeling 6. Anders
9.	EERSTE OPNAME GEGEVENS (Eenmalig bij eerste invulling, indien mogelijk bij eerste opname)	a. Datum van eerste opname: Dag — Maand — Jaar b. Opgenomen vanuit (bij eerste opname): 1. Eigen omgeving zonder thuiszorg 2. Eigen omgeving met thuiszorg 3. Verzorgingshuis 4. Verpleeghuis 5. Algemeen ziekenhuis 6. Psychiatrisch ziekenhuis, instelling voor geestelijk gehandicapten 7. Revalidatiecentrum 8. Anders
10.	HEROPNAME GEGEVENS (Alleen bij heropname)	a. Datum van heropname: Dag — Maand — Jaar b. Opgenomen vanuit (bij heropname): 1. Eigen omgeving zonder thuiszorg 2. Eigen omgeving met thuiszorg 3. Verzorgingshuis 4. Verpleeghuis 5. Algemeen ziekenhuis 6. Psychiatrisch ziekenhuis, instelling voor geestelijk gehandicapten 7. Revalidatiecentrum 8. Anders
11.	ONTSLAG GEGEVENS (Alleen bij ontslag--ook overlijden)	a. Datum van ontslag of overlijden: Dag — Maand — Jaar
	ONTSLAG GEGEVENS (Vervolgd)	b. Verblijfssituatie bij ontslag: 1. Naar eigen omgeving zonder thuiszorg dienstverlening 2. Naar eigen omgeving met thuiszorg dienstverlening 3. Verzorgingshuis 4. Ander verpleeghuis 5. Algemeen ziekenhuis 6. Psychiatrisch ziekenhuis, instelling voor geestelijk gehandicapten 7. Revalidatie-ziekenhuis 8. Overleden 9. Anderszins
12.	DEELNAME AAN DE BEOOR-DELING	a. Patiënt: 0. Nee 1. Ja b. Familie: 0. Nee 1. Ja 2. Heeft geen familie c. Belangrijk ander persoon: 0. Nee 1. Ja 2. Geen
13.	HANDTEKENINGEN VAN HEN DIE DE BEOORDELING HEBBEN UITGEVOERD:	

a. Handtekening van de beoordeling coördinerende verpleegkundige (teken hierboven)

b. Datum van handtekening Dag — Maand — Jaar

c. Andere Handtekeningen	Functie	Secties	Datum
d.			Datum
e.			Datum
f.			Datum
g.			Datum
h.			Datum

☐ = Indien blanco, vul dan een getal of letter in a. ☐ = Indien met letter, kruis dan het antwoord aan dat van toepassing is

Patiënt _____ Identificatienummer _____

SECTIE AB. PERSOONSGEGEVENS *(Eenmalig bij eerste invulling, indien mogelijk bij eerste opname)*

1.	**WOONDE (VOOR 1E OPNAME) ALLEEN**	0. Nee 1. Ja 2. In andere instelling	
2.	**POSTCODE (VOOR 1E OPNAME)**		
3.	**VOOR-AFGAAND VERBLIJF IN INSTEL-LINGEN IN DE LAATSTE 5 JAAR**	*(Kruis **de instellingen aan** waar de patiënt de laatste 5 jaar voorafgaand aan de eerste opname, zie item ABt, woonde)* Eerder verblijf in dit verpleeghuis a. Verblijf in een ander verpleeghuis b. Verblijf in andere instelling --Pensiontehuis, verzorgingshuis, begeleid wonen, groepstehuis c. Psychiatrische zorgsetting d. Zorgsetting voor geestelijk gehandicapten e. *GEEN VAN BOVENSTAANDE* f.	
4.	**VROEGERE BEROEP(EN) [Zet "/" tussen twee beroepen]**		
5.	**OPLEIDING** (*Hoogst behaalde niveau*)	1. Geen scholing 2. Lagere school/minder 3. MAVO/HAVO of vergelijkbaar 4. VWO 5. MBO 6. HBO 7. Universitaire opleiding	
6.	**TAAL**	(*Codeer het juiste antwoord*) **a.** Moedertaal 0. Nederlands 1. Andere taal **b. Indien andere taal, specificeer:**	
7.	**GEESTE-LIJKE GEZONDHEID**	Vermeldt het patiëntDOSSIER een geestelijke handicap, geesteszieke of enig andere ontwikkelingsbeperking? 0. Nee 1. Ja	
8.	**ZIEKTE-BEELDEN DIE SAMEN-HANGEN MET GEESTE-LIJKE HANDICAP**	(*Kruis de ziektebeelden aan die samenhangen met de geestelijke handicap, optraden voor het 22-ste jaar, en waarschijnlijk blijvend zijn*) N.v.t. —geen geestelijke handicap (Ga direct naar ABn) a. Geestelijke handicap van organische aard: Down's syndroom b. Autisme c. Epilepsie d. Ander organisch ziektebeeld in verband met geestelijke handicap e. Geestelijke handicap niet organisch f.	

SECTIE AC. GEWOONTEN ROUTINE *(Eenmalig bij eerste invulling, indien mogelijk bij eerste opname)*

1.	**GEWOONTEN ROUTINE** (*In het jaar voorafgaand aan DE DATUM VAN EERSTE OPNAME in dit verpleeg-huis, of het laatste jaar thuis indien opgenomen vanuit een ander verpleeghuis of verpzorgings-huis*)	(*Kruis aan. Bij alles ONBEKEND, kruis dan alleen het laatste hokje aan.*) **DAGRITME** Bleef 's avonds laat op (bijv. tot na 9 uur) a. Sliep regelmatig overdag (tenminste 1 uur) b. Ging tenminste 1x per week uit c. Hield zich bezig met hobby's, lezen of andere vaste dagroutine d. Was meestal alleen of keek meestal televisie e. Verplaatste zich zelfstandig binnenshuis (evt. met hulpmiddelen) f. Gebruikte tenminste dagelijks tabaksproducten g. *GEEN VAN BOVENSTAANDE* h. **EETGEWOONTEN** Had voorkeur voor bepaald voedsel i. At elke dag of de meeste dagen tussendoor j. Dronk minstens 1x per week alcohol k. *GEEN VAN BOVENSTAANDE* l. **ADL-GEWOONTEN** Liep een groot deel van de dag in nachtkleding m. Stond bijna elke nacht op om naar het toilet te gaan n. Had een onregelmatige stoelgang o. Nam een bad in plaats van een douche p. Nam een douche of bad in de middag of avond q. *GEEN VAN BOVENSTAANDE* r. **BETROKKENHEID** Had dagelijks contact met familie/vrienden s. Ging vaak naar de kerk, moskee, synagoge (enz.) t. Putte kracht uit het geloof u. Huisdier als dagelijks gezelschap v. Nam deel aan groepsactiviteiten w. *GEEN VAN BOVENSTAANDE* x. **ONBEKEND** —Patiënt/familie niet in staat om informatie te geven y.	

Patiënt _____ Identificatienummer _____

MINIMUM DATA SET (MDS) — *VERSIE 2.0*
VOOR BEOORDELING EN ZORGBEPALING VAN VERPLEEGHUISPATIENTEN
FORMULIER ***VOOR EEN VOLLEDIGE BEOORDELING***
(Toestand in de laatste 7 dagen, tenzij een ander tijdsbestek is aangegeven)

SECTIE A. IDENTIFICATIE- EN ACHTERGROND-INFORMATIE

3. BEOORDELINGS REFERENTIE-DATUM
a. *Einddatum MDS observatieperiode*
Dag — Maand — Jaar
b. Oorspronkelijk (o) of zoveelste gecorrigeerd formulier (vul getal in)

5. BURGERLIJKE STAAT
1. Nooit gehuwd 3. Partner/significant andere 5. Uiteen
2. Gehuwd 4. V erweduwd 6. Gescheiden

9. VERANTWOORDELIJKHEID/ VOOGD
(*Kruis aan*)
Voogd a.
Ander wettelijk toezicht b.
Curator: gezondheidzorg c.
Curator: financieel d.
Familielid verantwoordelijk e.
Patiënt zelf verantwoordelijk f.
GEEN VAN BOVENSTAANDE g.

10. AFGEGEVEN BESCHIKKINGEN
(*Kruis de items aan waar in het medisch dossier iets over staat opgetekend*)
Levenstestament a.
Niet reanimeren b.
Niet naar ziekenhuis c.
Donorcodicil d.
Verzoek om autopsie e.
Voedingsbeperkingen f.
Beperkingen bij medicijntoediening g.
Andere behandelbeperkingen h.
GEEN VAN BOVENSTAANDE i.

SECTIE B. COGNITIEF FUNCTIONEREN

1. COMATEUS
(*Voortdurende vegatieve toestand/ niet waarneembaar bewustzijn*)
0. Nee 1. Ja (**Ja, ga dan direct naar Sectie G**)

2. GEHEUGEN/ PASSIEF
(*Zich herinneren wat vroeger geleerd is of bekend was*)
a. Korte-termijn geheugen —schijnt/lijkt na 5 min. nog te herinneren
0. Geheugen goed 1. Geheugenprobleem
b. Lange-termijn geheugen—schijnt/lijkt verre verleden te herinneren
0. Geheugen goed 1. Geheugenprobleem

3. GEHEUGEN/ ACTIEF
(*Kruis aan hetgeen de patiënt zich gewoonlijk gedurende de laatste 7 dagen kon herinneren*)
Huidig jaargetij a.
Ligging eigen kamer b.
Namen/gezichten verzorg c.
Dat hij/zij in een verpleeghuis is d.
GEEN VAN BOVENSTAANDE e.

4. COGNITIEVE VAARDIGHEDEN VOOR DE DAGELIJKSE BESLUITVORMING
(*Nam beslissingen over taken van dagelijks leven*)
0. *ZELFSTANDIG* —beslissingen samenhangend/redelijk
1. *VERMINDERD ZELFSTANDIG* —slechts in nieuwe situaties enige moeite
2. *MATIG GESTOORD* —slechte beslissingen; aanwijzingen/toezicht nodig
3. *ERNSTIG GESTOORD* —nam zelden of nooit beslissingen

5. INDICATOREN VAN DELIER—PERIODIEK GESTOORD DENKEN/ BEWUSTZIJN
(*Codeer het gedrag van de laatste 7 dagen.)*
0. Gedrag niet aanwezig
1. Gedrag aanwezig, maar niet recent begonnen
2. Gedrag aanwezig, bewoner lijkt de laatste 7 dagen anders te functioneren (bv., gedrag is net begonnen of erger geworden)

a. GEMAKKELIJK AFGELEID—(bv., moeite met aandacht opbrengen; raakt gemakkelijk op dwaalspoor)
b. WAARNEMEN, BEWUSTZIJN VAN OMGEVING WISSELEND—(bv. beweegt de lippen of praat tegen een niet-aanwezig persoon; denkt ergens anders te zijn; haalt de dag en de nacht door elkaar)
c. EPISODEN VAN ONSAMENHANGEND PRATEN—(bv., spraak mist samenhang, is onzinnig, niet ter zake, of gaat van de hak op de tak; raakt de gedachtengang kwijt)
d. PERIODEN VAN ONRUST—(bv ., frunikken of krabben aan de huid, aan kleding, servetten, enz.; vaak van lichaamshouding veranderen; herhaald bewegingen uitvoeren of schreeuwen)
e. PERIODEN VAN LUSTELOOSHEID—(bv., sloom zijn; voor zich uit staren; moeilijk wakker te krijgen; weinig lichaamsbeweging)
f. GEESTELIJK FUNCTIONEREN WISSELT GEDURENDE DAG—(bv., soms beter, soms slechter; gedrag soms wel, soms niet)

6. VERANDERING COGNITIEF FUNCTIONEREN
De cognitieve toestand, vaardigheden of vermogens van de patiënt zijn ten opzichte van **90 dagen geleden** (of sinds de laatste beoordeling daarna) veranderd
0. Geen verandering 1. Verbeterd 2. Verslechterd

SECTIE C. COMMUNICATIEPATRONEN/GEHOOR

1. HOREN
(*met gehoorapparaat, indien gebruikt*)
0. *HOORT NAAR BEHOREN* —normaal gesprek, TV, telefoon
1. *ENIGSZINS MOEITE* wanneer het niet rustig is
2. *HOORT SLECHTS IN SPECIALE OMSTANDIGHEDEN* —spreker moet toonhoogte aanpassen en duidelijk spreken
3. *ERNSTIG GESTOORD* /bruikbare gehoorfunctie afwezig

2. COMMUNICATIE-HULP-MIDDELEN/ TECHNIEKEN
(*Kruis aan wat gedurende de laatste 7 dagen van toepassing is*)
Gehoorapparaat, aanwezig en gebruikt a.
Gehoorapparaat, aanwezig, maar niet regelmatig gebruikt b.
Gebruikt andere communicatietechnieken (bv., liplezen) c.
GEEN VAN BOVENSTAANDE d.

3. MANIEREN VAN ZICH UITEN
(*Kruis aan hoe patiënt behoeften kenbaar maakt*)
Spreken a.
Schrijven van een briefje b.
Officiële gebarentaal of BRAILLE c.
Tekens/gebaren/geluiden d.
Communicatiebord e.
Anderszins f.
GEEN VAN BOVENSTAANDE g.

4. ZICHZELF DUIDELIJK MAKEN
(*Maakt de inhoud van boodschap duidelijk—hoe dan ook*)
0. *WORDT BEGREPEN*
1. *GEWOONLIJK BEGREPEN* —moeite bij het vinden van woorden of het afmaken van gedachten
2. *SOMS BEGREPEN* —kan alleen concrete verzoeken doen
3. *WORDT ZELDEN OF NOOIT BEGREPEN*

5. DUIDELIJKHEID VAN SPREKEN
(*Codeer het spreken in de laatste 7 dagen*)
0. *DUIDELIJK SPREKEN* —duidelijke, verstaanbare woorden
1. *ONDUIDELIJK SPREKEN* —slissen, mompelen
2. *SPREEKT NIET* —geen gesproken woorden

6. VERMOGEN OM ANDEREN TE BEGRIJPEN
(*Begrijpen van verbale informatie—hoe dan ook*)
0. *BEGRIJPT*
1. *BEGRIJPT GEWOONLIJK* —kan een deel of de bedoeling van de boodschap missen
2. BEGRIJPT SOMS—geeft passende reactie op eenvoudige, directe communicatie
3. *BEGRIJPT ZELDEN OF NOOIT*

7. VERANDERING COMMUNICATIE/ HOREN
Het vermogen van de patiënt zich te uiten, te begrijpen of informatie te horen is vergeleken met **90 dagen geleden** (of sinds de laatste beoordeling daarna) veranderd
0. Geen verandering 1. Verbeterd 2. Verslechterd

SECTIE D. GEZICHTSVERMOGEN

1. KUNNEN ZIEN
(*Gezichtsvermogen bij voldoende licht, eventueel met bril*)
0. *VOLDOENDE* —ziet details, kan alle letters in kranten en boeken lezen
1. *BEPERKT* —ziet wel grote, maar niet drukletters van normale grootte
2. *MATIG BEPERKT* —beperkt gezichtsvermogen, kan geen krantenkoppen zien, maar kan wel voorwerpen herkennen
3. *STERK BEPERKT* —het is de vraag of voorwerpen worden herkend, maar de ogen lijken wel voorwerpen te volgen
4. *ZEER ERNSTIG BEPERKT* —ziet niets of alleen licht, kleuren of vormen; ogen lijken geen voorwerpen te volgen

2. GEZICHTSBEPERKING/ MOEILIJKHEDEN
Gezichtsveldproblemen—verminderd perifeer zien (bv., laat voedsel op één helft van dienblad liggen, botst tegen mensen en voorwerpen op, heeft moeite om stoel te vinden bij het gaan zitten) a.
Ervaart iets van het volgende: ziet kransen of ringen rond licht–bronnen; lichtflitsen; "waas" voor de ogen b.
GEEN VAN BOVENSTAANDE c.

3. GEZICHTSMIDDELEN
Bril; contactlenzen; vergrootglas
0. Nee 1. Ja

= Indien blanco, vul dan een getal of letter in a. = Indien met letter, kruis dan het antwoord aan dat van toepassing is

Patiënt _____ Identificatienummer _____

SECTIE E. STEMMINGS- EN GEDRAGSPATRONEN

1. INDICATOREN VAN DEPRESSIE, ANGST, BEDROEFDE STEMMING

(*Codeer de in de laatste 30 dagen waargenomen aanwijzingen, ongeacht de vermoedelijke oorzaak*)
0. Indicator in de laatste 30 dagen niet vertoond
1. Indicator van dit type 1 tot 5 dagen per week vertoond
2. Indicator dagelijks of bijna dagelijks vertoond (6, 7 dagen per week)

VERBALE UITINGEN VAN LIJDEN

a. Negatieve uitspraken—"***Het doet er allemaal niet toe; Was ik maar dood; Wat voor zin heeft het; Het spijt me zolang te hebben geleefd; Laat me sterven*** "

b. Aldoor vragen—"***Waarga ik heen; Wat doe ik dan?*** "

c. Aldoor uitroepen—Om hulp roepen, ("***God sta me bij***")

d. Voortdurend boos zijn op zichzelf of op anderen—Zich gemakkelijk ergeren, boos op verblijf in verpleeghuis, boos op de ontvangen zorg

e. Zelfverwijt—"***Ik ben niets; Ik ben niemand tot nut***"

f. Uitingen van angst die niet reëel lijken—Bang om in de steek te worden gelaten, alleen te zijn, samen met anderen te zijn

g. Aldoor zeggen dat iets vreselijks gaat gebeuren—Denken dat men op het punt staat dood te gaan, een hartaanval heeft

h. Aldoor klagen over gezondheid—Om de dokter blijven vragen, obsessief bezorgd zijn over lichaamsfuncties

i. Aldoor zorgelijk klagen (niet met gezondheid samenhangend)—Zoekt steeds aandacht/geruststelling over de dagindeling, maaltijden, de was, kleren, de omgang met anderen

SLAAPPROBLEMEN

j. Ochtendhumeur

k. Slapeloosheid/ verandering in gebruikelijk slaappatroon

BEDROEFD, ANGSTIG, APATHISCH UITERLIJK

l. Droevige, pijnlijke, zorglijke gelaatsuitdrukking—Diepe rimpels

m. Huilen, gemakkelijk tranen

n. Motorische onrust—Ijsberen, handenwringen, rusteloos zijn, friemelen, plukken

INTERESSEVERLIES

o. Terugtrekken uit activiteiten—Geen interesse meer in wat men altijd deed of met familie/vrienden zijn

p. Minder omgang

2. HARDNEKKIGE STEMMINGSSTOORNIS

Een of meer aanwijzingen van droevige of angstige stemming die **in de laatste 7 dagen niet gemakkelijk door "opvrolijken", troosten of geruststellen waren te veranderen**
0. Geen aanwijzingen 1. Aanwijzingen, maar makkelijk veranderd 2. Aanwijzingen, niet makkelijk veranderd

3. VERANDERING STEMMING

De gemoedstoestand van de patiënt is ten opzichte van **90 dagen geleden** (of sinds de laatste beoordeling daarna) veranderd
0. Geen verandering 1. Verbeterd 2. Verslechterd

4. GEDRAGSSYMPTOMEN

(A) ***De frequentie van het gedrags symptoom in de laatste 7 dagen***
0. Gedrag kwam in de laatste 7 dagen niet voor
1. Gedrag kwam 1 tot 3 dagen in de laatste 7 dagen voor
2. Gedrag kwam 4 tot 6 dagen voor, maar niet elke dag
3. Gedrag kwam dagelijks voor

(B) ***De veranderbaarheid van het gedrags symptoom de laatste 7 dagen***
0. Gedrag afwezig OF gedrag gemakkelijk veranderd
1. Gedrag was niet gemakkelijk te veranderen

	(A)	(B)
a. ZWERFGEDRAG (liep doelloos rond, zich schijnbaar niet bewust van behoeften of gevaar)		
b. VERBAAL LASTIGVALLEN (bedreigde anderen, schreeuwde naar ze, vloekte naar ze)		
c. LICHAMELIJK LASTIGVALLEN (sloeg anderen, duwde, krabde, viel seksueel lastig)		
d. SOCIAAL ONAANGEPAST/STOREND GEDRAG (maakte storende geluiden, lawaai, gegil, zelfverwonding, vertoonde seksueel gedrag of kleedde zich in het openbaar uit, smeerde/gooide met eten/feces, hamsterde, snuffelde in andermans spullen)		
e. VERZET TEGEN ZORG (weigerde medicijnen/ injecties, hulp bij ADL of bij eten)		

5. VERANDERING GEDRAG

De gedragstoestand van de patiënt is ten opzichte van **90 dagen geleden** (of sinds de laatste beoordeling daarna) veranderd
0. Geen verandering 1. Verbeterd 2. Verslechterd

SECTIE F. PSYCHOSOCIAAL WELBEVINDEN

1. GEVOEL VAN INITIATIEF/ BETROKKENHEID

Op gemak in omgang met anderen	a.
Op gemak bij geplande of gestructureerde activiteiten	b.
Op gemak bij zelf-opgezette activiteiten	c.
Stelt zich eigen doelen	d.
Zoekt betrokkenheid in instelling (maakt/houdt vrienden; neemt deel aan groepsactiviteiten; nieuwe activiteiten; helpt bij activiteiten van godsdienstige aard	e.
Neemt uitnodigingen aan voor de meeste groepsactiviteiten	f.
GEEN VAN BOVENSTAANDE	g.

2. ONGEMAKKELIJKE OMGANG MET ANDEREN

Bedekt/openlijk conflict met of herhaalde kritiek op zorgverleners	a.
Niet blij met kamergenoot	b.
Niet blij met andere patiënten dan kamergenoot	c.
Uit openlijk conflict/boosheid met familie/vrienden	d.
Geen persoonlijk contact met familie/vrienden	e.
Recent verlies van naast familielid/vriend	f.
Past zich niet gemakkelijk aan veranderende routines aan	g.
GEEN VAN BOVENSTAANDE	h.

3. VROEGERE ROLLEN

Sterke vereenzelviging met vroegere rollen en status	a.
Uit droefheid/boosheid/leegte over verloren rollen/status	b.
Patiënt ervaart de dagelijkse routine (gewoonten, activiteiten) als geheel verschillend van vroeger thuis	c.
GEEN VAN BOVENSTAANDE	d.

SECTIE G. LICHAMELIJK FUNCTIONEREN EN STRUCTURELE PROBLEMEN

1. (A) ZELF-DOEN BIJ ADL—(***Codeer het ZELF-DOEN van de patiënt IN ALLE DIENSTEN gedurende de laatste 7 dagen —Niet het gereedzetten van dingen***)

0. ***ZELFSTANDIG*** —Geen hulp of toezicht —OF— Hulp/toekijken slechts 1 of 2 keer gedurende de laatste 7 dagen
1. TOEZICHT—Toekijken, aanmoediging of aanwijzingen 3 of meer keer gedurende de laatste 7 dagen —OF— Toezicht (3 of meer keer) plus slechts 1 of 2 keer lichamelijke ondersteuning gedurende de laatste 7 dagen
2. ***BEPERKTE HULP*** —Patiënt erg betrokken bij activiteit; ontving 3 of meer keer lichamelijke hulp bij het manoeuvreren van ledematen of ontving andere niet-gewichtsontlastende hulp —OF—Meer hulp slechts 1 of 2 keer gedurende de laatste 7 dagen
3. ***UITGEBREIDE HULP*** —Terwijl de patiënt een deel van de activiteit zelf uitvoerde, werd de volgende hulp in de laatste 7 dagen 3 keer of vaker gegeven:
—Gewichtsontlastende hulp
—Hulp geheel door zorgverleners uitgevoerd, maar niet gedurende alle 7 dagen
4. ***TOTAAL AFHANKELIJK*** —Geheel door zorgverleners uitgevoerd gedurende 7 dagen
8. ***ACTIVITEIT KWAM*** gedurende de gehele 7 dagen NIET VOOR

(B) DE GEGEVEN ADL-HULP—(***Codeer de MAXIMAAL GEGEVEN HULP IN ALLE DIENSTEN gedurende de laatste 7 dagen; codeer ongeacht het vastgelegde zelf-doen van de patiënt***)

	(A) ZELF-DOEN	(B) HULP
0. Zonder klaarzetten of lichamelijke hulp door zorgverleners		
1. Slechts hulp in de vorm van klaarzetten		
2. Lichamelijke hulp door 1 persoon		
3. Lichamelijke hulp door 2 of meer personen		
8. Activiteit kwam tijdens de gehele 7 dagen niet voor		
a. BEWEEGLIJKHEID IN BED — Hoe patiënt uit/in de lighouding komt, zich omdraait, en in bed de lichaamshouding aanneemt		
b. TRANSFER — Hoe de patiënt tussen oppervlakten beweegt—in/uit bed, stoel, rolstoel, staan (NIET in/uit bad/toilet)		
c. LOPEN IN DE KAMER — Hoe de patiënt van plek naar plek in zijn/haar kamer loopt		
d. LOPEN OP DE GANG — Hoe de patiënt op de gang van de afdeling loopt		
e. VERPLAATSEN OP AFDELING — Hoe de patiënt zich van plaats tot plaats in zijn/haar kamer en de gang ernaast op dezelfde verdieping begeeft. Bij gebruik van rolstoel, hoe zelfstandig daarmee		
f. VERPLAATSEN BUITEN DE AFDELING — Hoe de patiënt zich naar buiten de afdeling begeeft en terugkeert (bv., eet-, activiteiten- of behandelruimten). **Als er maar één verdieping is** , hoe de patiënt dan naar verafgelegen ruimten gaat. Bij gebruik van rolstoel, hoe zelfstandig de patiënt daarmee is		
g. KLEDEN — Hoe de patiënt alle **uitgaanskledingstukken** aantrekt, dichtknoopt, uittrekt, inclusief het aan-/uitdoen van een prothese		
h. ETEN — Hoe de patiënt eet en drinkt (ongeacht vaardigheid). Dit omvat ook het nuttigen van voedsel op ander manieren (bv., sondevoeding, totale parenterale voeding)		
i. TOILETGEBRUIK — Hoe de patiënt de toiletruimte (of toiletstoel, pot, urinaal) gebruikt; op/van het toilet komt, doorspoelt, luier wisselt, omgaat met stoma/catheter, kleren in orde brengt		
j. PERSOONLIJKE HYGIENE — Hoe de patiënt de persoonlijke hygiëne handhaaft, inclusief haarkammen, tanden poetsen, scheren, makeup aanbrengen, gezicht, handen en bilnaad wassen/drogen (NIET baden en douchen)		

2. BADEN — Hoe de patiënt in bad gaat/doucht, zich afsponst en in/uit bad of douche komt (NIET het wassen van rug en haar.) ***Codeer de grootste afhankelijkheid bij het zelf-doen en bij hulp*** .

	(A)	(B)
(A) De ZELF-DOEN codes hierbij zijn:		
0. Zelfstandig—Geen hulp gegeven		
1. Toezicht—Alleen maar toekijk-hulp		
2. Lichamelijke hulp beperkt tot transfers		
3. Lichamelijke hulp bij gedeelte van baadactiviteit		
4. Totale afhankelijkheid		
8. Activiteit kwam gedurende de gehele 7 dagen niet voor (***Codes voor hulp bij baden, zie item 1, code B***)		

Patiënt _____ Identificatienummer _____

3. TEST VOOR EVENWICHT (zie Gebruikershandboek)

(*Codeer wat de patiënt in de* ***laatste 7 dagen*** kon)

0. Handhaafde stand zoals in de test vereist
1. Wankelde, maar was in staat om zonder hulp het evenwicht te hervinden
2. Gedeeltelijke lichamelijke ondersteuning tijdens test; of gaat staan (zitten) maar niet zoals de test dat verlangt
3. Niet in staat om de test te doen zonder lichamelijke hulp

a. Evenwicht bij staan
b. Evenwicht bij zitten—houding, controle over het bovenlijf

4. FUNCTIONELE BEWEGINGSBEPERKING (zie Gebruikershandboek)

(*Codeer de beperkingen gedurende de* ***laatste 7 dagen*** *die de dagelijkse functies belemmerden of een risico voor verwondingen vormden*)
(A) ***BEWEGINGSUITSLAG*** **(B)** ***WILLEKEURIGE BEWEGING***
0. Geen beperking 0. Geen verlies
1. Beperking aan één kant 1. Gedeeltelijk verlies
2. Beperking aan beide kanten 2. Volledig verlies

	(A)	(B)
a. Nek		
b. Arm—Inclusief schouder of elleboog		
c. Hand—Inclusief pols of vingers		
d. Been—Inclusief heup of knie		
e. Voet—Inclusief enkel of tenen		
f. Andere beperking of verlies		

5. MANIEREN VAN ZICH VERPLAATSEN

(*Kruis aan* ***wat gedurende de laatste 7 dagen van toepassing is***)

a. Stok/rollator/kruk
b. Zelfvoortbewogen rolstoel
c. In rolstoel geduwd
d. Rolstoel belangrijkste manier om zich te verplaatsen
e. ***GEEN VAN BOVENSTAAND***

6. MANIEREN VAN TRANSFER

(*Kruis aan* ***wat gedurende de laatste 7 dagen van toepassing is***)

a. Altijd of meestal in bed
b. Bedhekken voor beweeglijkheid in bed of bij transfers
c. Met de hand getild
d. Mechanische getild
e. Hulpmiddel (bv. glijplank, papegaai, stok, driepoot, tuigje)
f. ***GEEN VAN BOVENSTAAND***

7. TAAKOPDELING

Sommige of alle ADL-activiteiten werden gedurende de **laatste 7 dagen** in deeltaken opgedeeld zodat de patiënt ze kon uitvoeren
0. Nee 1. Ja

8. POTENTIEEL VOOR ADL-REVALIDATIE

Patiënt denkt dat hij/zij is in staat is tot grotere zelfstandigheid in tenminste enkele van de ADL's — a.
De directe zorgverleners denken dat de patiënt in staat is tot grotere zelfstandigheid in tenminste enkele van de ADL's — b.
De patiënt kan taken/activiteiten uitvoeren, maar is erg langzaam — c.
Er is een verschil in zelf-doen bij ADL of Hulp bij ADL in de ochtend ten opzichte van de avond — d.
GEEN VAN BOVENSTAANDE — e.

9. VERANDERING FUNCTIONEREN BIJ ADL

Het zelf-doen bij ADL van de patiënt is ten opzichte van **90 dagen geleden** (of sinds de laatste beoordeling daarna) veranderd
0. Geen verandering 1. Verbeterd 2. Verslechterd

SECTIE H. CONTINENTIE IN DE LAATSTE 14 DAGEN

1. CONTINENTIEZELFBEHEERSING CATEGORIEËN (***Codeer het DOEN VAN DE PATIËNT OVER ALLE DIENSTEN HEEN***)

0. ***CONTINENT—*** Volledige beheersing ***[inbegrepen het gebruik van een verblijfscatheter of stoma die geen urine of feces lekken]***

1. ***GEWOONLIJK CONTINENT*** —BLAAS, incontinentie-gebeurtenissen een keer per week of minder; DARMEN, minder dan een keer per week

2. ***AF EN TOE INCONTINENT*** —BLAAS, 2 of meer keren per week maar niet dagelijks; DARMEN, een keer per week

3. ***VAAK INCONTINENT*** —BLAAS, neigde naar dagelijkse incontinentie, maar enige beheersing aanwezig (bv., tijdens de dagdienst); DARMEN, 2-3 keer per week

4. ***INCONTINENT*** —Had ontoereikende beheersing BLAAS, dagelijks en veelvuldig; DARMEN, altijd of bijna altijd

a. CONTINENTIE VAN DE DARMEN — Beheersing over ontlasting, eventueel met hulpmiddel of dankij ontlastingsbeheersing training

b. CONTINENTIE VAN DE BLAAS — Beheersing over urineblaasfunctie (bij nalekken sijpelt er niets door de onderbroek), eventueel met hulpmidden (bv., Foley-catheter) of dankij continentie-training

2. STOELGANG

Stoelgang regelmatig—tenminste eenmaal per drie dagen — a.
Verstopping — b.
Diarree — c.
Faecesprop — d.
GEEN VAN BOVENSTAANDE — e.

3. HULPMIDDELEN EN PROGRAMMA'S

Een toiletroosterschema — a.
Opnieuw trainen van de blaas — b.
Uitwendig (condoom)catheter — c.
Verblijfscatheter — d.
Intermitterende catheterisatie — e.
Ging niet op toilet/toiletstoel/urinaal — f.
Gebruikte luiers/slips — g.
Klysma/blaasspoeling — h.
Heeft een stoma — i.
GEEN VAN BOVENSTAANDE — j.

4. VERANDERING URINE-CONTINENTIE

De urine-continentie van de patiënt is ten opzichte van **90 dagen geleden** (of sinds de laatste beoordeling daarna) veranderd
0. Geen verandering 1. Verbeterd 2. Verslechterd

SECTIE I. DIAGNOSEN VAN ZIEKTEN

Kruis slechts de ziekten aan die verband houden met de huidige toestand in ADL, cognitie, stemming en gedrag, medische behandelingen, monitoring van de verpleging, of sterfterisico. (Geef geen opsomming van niet-actieve diagnosen)

1. ZIEKTEN (***Indien géén van toepassing, dan GEEN VAN BOVENSTAAND***)

ENDOCRIEN/MET ABOLISME/VOEDING
Diabetes mellitus — a.
Hyperthyreoïdie — b.
Hypothyreoïdie — c.
HART/BLOEDCIRCULATIE
Arteriosclerotische hartaandoening(ASHD) — d.
Hartritmestoornissen — e.
Decompensatio cordis — f.
Trombose van diepe venen — g.
Hoge bloeddruk — h.
Lage bloeddruk — i.
Perifere vaatziekte — j.
Overige hart- en vaataand. — k.
BEWEGINGSSTELSEL
Reumatische aandoeningen — l.
Heupfractuur — m.
Mist ledemaat (bv., amputatie) — n.
Osteoporose — o.
Pathologische botfractuur — p.
NEUROLOGIE
Ziekte van Alzheimer — q.
Afasie — r.
Hersenverlamming — s.
Cerebrovasculair accident (CVA/beroerte) — t.
Dementie anders dan de ziekte van Alzheimer — u.
Hemiplegie/Hemiparese — v.
Multiple sclerose — w.
Paraplegie — x.
Ziekte van Parkinson — y.
Quadriplegie — z.
Toevallen (o.a. epilepsie) — aa.
Pasagère cerebrale ischemie — bb.
Traumatisch hersenletsel — cc.
PSYCHIA TRIE/STEMMING
Angststoornis — dd.
Depressie — ee.
Manisch depressief — ff.
Schizofrenie — gg.
ADEMHALING
Astma — hh.
Emfyseem/COPD — ii.
ZINTUIGEN
Cataracten — jj.
Diabetes retinopathie — kk.
Glaucoom — ll.
Macula degeneratie — mm.
OVERIGE
Allergieën — nn.
Bloedarmoede — oo.
Kanker — pp.
Nierinsufficiëntie — qq.
GEEN VAN BOVENSTAAND — rr.

2. INFECTIES (***Kruis aan wat gedurende de laatste 7 dagen van toepassing is***)

Antibiotica-resistente infectie (bv., Methicilline resistente staphilococcen) — a.
Clostridium difficile (c. diff.) — b.
Conjunctivitis — c.
HIV-infectie — d.
Pneumonie — e.
Infectie van de luchtwegen — f.
Sepsis — g.
Seksueel overdraagb. aand. — h.
Tuberculose — i.
Urineweginfectie **in de laatste 30 dagen** — j.
Virale hepatitis — k.
Wondinfectie — l.
GEEN VAN BOVENSTAAND — m.

3. ANDERE CURRENTE OF GEDETAILLEERDERE DIAGNOSEN EN ICD-9-CM CODES

a. _____ . _____
b. _____ . _____
c. _____ . _____
d. _____ . _____
e. _____ . _____

SECTIE J. GEZONDHEIDSPROBLEMEN

1. PROBLEMEN (***Kruis alle problemen van de laatste 7 dagen aan tenzij een ander tijdsbestek is aangegeven***)

VOCHTBALANSINDICATOREN
Gewichtstoename/verlies van twee of meer kilo binnen 7 dagen — a.
Kan niet op de rug liggen vanwege kortademigheid — b.
Uitgedroogd; vochtverlies groter dan vochtopname — c.
Onvoldoende vocht; nam **NIET** alle/bijna alle vocht dat in de **laatste 3 dagen** werd aangeboden — d.
ANDERE
Wanen — e.
Duizeligheid/draaierigheid — f.
Oedeem — g.
Koorts — h.
Hallucinaties — i.
Inwendige bloeding — j.
Recidiverende longaspiraties in de **laatste 90 dagen** — k.
Kortademigheid — l.
Syncope (wegrakingen) — m.
Onstandvastig ter been — n.
Braken — o.
GEEN VAN BOVENSTAAND — p.

2. PIJNSYMPTOMEN (***Codeer het hoogst ervaren pijnniveau in de laatste 7 dagen***)

a. FREQUENTIE waarmee patiënt over pijn klaagt of tekenen van pijn vertoont
0. Geen pijn (***ga naar J4***)
1. Minder dan dagelijks pijn
2. Dagelijks pijn

b. Pijn-**INTENSITEIT**
1. Lichte pijn
2. Matige pijn
3. Van tijd tot tijd vreselijke of ondraaglijke pijn

Patiënt _____ Identificatienummer_____

3.	**PLAATS VAN DE PIJN**	*(Bij pijn kruis dan alle pijnplekken aan van de laatste 7 dagen)*		
		Rugpijn	a.	
		Botpijn	b.	
		Pijn in de borst terwijl men normale dingen doet	c.	
		Hoofdpijn	d.	
		Pijn in de heup	e.	
		Pijn vanwege chirurgische wond		f.
		Gewrichtspijn (niet heup)		g.
		Pijn aan zachte weefsels (bv., wond, spier)		h.
		Maagpijn		i.
		Andere pijn		j.
4.	**ONGE-VALLEN**	*(Kruis aan wat van toepassing is)*		
		Viel in de **laatste 30 dagen**	a.	
		Viel in de **laatste 31-180 dagen**	b.	
		Heupfractuur in de **laatste 180 dagen**		c.
		Andere fractuur in de **laatste 180 dagen**		d.
		GEEN VAN BOVENSTAANDE		e.
5.	**STABILITEIT VAN DE GEZOND-HEIDS-PROBLEMEN**	Door problemen/ziekten zijn de cognitie-, ADL-, stemmings- of gedrags-functies onstabiel—(wisselvallig, precair, verergerend)		a.
		Patiënt maakt een acute episode of opleving mee van een terugkerend of chronisch gezondheidsprobleem		b.
		Eindstadiumziekte, 6 maanden of korter te leven		c.
		GEEN VAN BOVENSTAANDE		d.

SECTIE K. VOEDINGSTOESTAND

1.	**MOND-PROBLEMEN**	Kauwprobleem		a.
		Slikprobleem		b.
		Mondpijn		c.
		GEEN VAN BOVENSTAANDE		d.
2.	**LENGTE EN GEWICHT**	*Noteer (a.) lengte in cm's en (b.) gewicht in kg's . Baseer het gewicht op de meest recente meting in de laatste 30 dagen ; meet het gewicht op de standaardwijze—bv., in de ochtend, na de toiletgang, vóór het ontbijt, met schoenen uit, in nachtkledij*		
		a. LEN (cm.)		**b.** GEW (kg.)
3.	**VERANDE-RING IN GEWICHT**	**a. Gewichtsverlies** —5 % or meer in de l **aatste 30 dagen** ; of 10 % of meer in de **laatste 180 dagen**		
		0. Nee 1. Ja		
		b. Gewichtstoename —5 % or meer in de l **aatste 30 dagen** ; of 10 % of meer in de **laatste 180 dagen**		
		0. Nee 1. Ja		
4.	**EET-PROBLEMEN**	Klaagt over de smaak van veel van het voedsel	a.	
		Regelmatig of herhaaldelijk klagen over honger	b.	
		Laat bij de meeste maaltijden 25% of meer van eten staan		c.
		GEEN VAN BOVENSTAANDE		d.
5.	**VOEDINGS-AANPAK**	*(Kruis aan wat in de laatste 7 dagen van toepassing is)*		
		Parenterale-/IV-voeding	a.	
		Voedingssonde	b.	
		Mechanisch bewerkt dieet	c.	
		Voeding met spuit (oraal)	d.	
		Therapeutisch dieet	e.	
		Voedingssupplement tussen maaltijden		f.
		Vastgezet bord, aangepast bestek, enz.		g.
		Neemt deel aan gewichts-veranderingskuur		h.
		GEEN VAN BOVENSTAANDE		i.
6.	**PARENTE-RALE OF ENTERALE VOEDSEL-OPNAME**	*(Ga naar Sectie L als 5a of 5b beide niet zijn aangekruist)*		
		a. Codeer het aandeel in **calorieën** dat de patiënt door parenterale- of sondevoedingen in de **laatste 7 dagen** ontving 0. Geen 3. 51 - 75% 1. 1 - 25% 4. 76 - 100% 2. 26 - 50%		
		b. Codeer de gem. IV- of sonde- **vochtopname** in de **laatste 7 dagen** 0. Geen 3. 1001 - 1500 cc/dag 1. 1 - 500 cc/dag 4. 1501 - 2000 cc/dag 2. 501 - 1000 cc/dag 5. 2001 en meer cc/dag		

SECTIE L. TOESTAND VAN DE MOND/GEBIT

1.	**TOESTAND EN ZIEKTE-PREVENTIE VAN DE MOND**	Brokstukjes (zacht, gemakkelijk te verwijderen) aanwezig in de mond voor het naar bed gaan 's avonds		a.
		Heeft een kunstgebit en/of uitneembare brug		b.
		Enige/alle eigen tanden kwijt—heeft geen of gebruikt geen kunstgebit (of gedeeltelijke gebitsplaten)		c.
		Afgebroken, losse of rotte tanden		d.
		Ontstoken tandvlees; opgezwollen of bloedend tandvlees; abcessen in de mond; zweren of uitslag		e.
		Dagelijks schoonmaken van tanden/kunstgebit—door de patiënt zelf of door zorgverleners		f.
		GEEN VAN BOVENSTAANDE		g.

SECTIE M. CONDITIE VAN DE HUID

				Aantal op stadium
1.	**ZWEREN (Waardoor dan ook)**	*(Noteer het aantal zweren op elk stadium—ongeacht de oorzaak. Als er geen zweer is, codeer dan "0" (nul). Codeer al wat in de laatste 7 dagen van toepassing is. Code 9 = 9 of meer.) [Een volledig lichamelijk onderzoek is noodzakelijk.]*		
		a. Stadium 1. Een blijvend stuk rode huid (zonder dat de huid kapot is) dat niet verdwijnt wanneer de druk erop is opgeheven.		
		b. Stadium 2. Een gedeeltelijk dikteverlies van de huid dat zich klinisch als een ontvelling, blaar of ondiep gat voordoet		
		c. Stadium 3. De volledige huiddikte is verloren gegaan. De onder-huidse weefsels liggen bloot. Dit doet zich voor als een diep gat met of zonder ondermijning van naastgelegen weefsel		
		d. Stadium 4. De volledige huiddikte en het onder:huids weefsel is verloren gegaan. Spieren en/of bot liggen bloot.		
2.	**SOORT ZWEER**	*(Voor elke soort zweer, codeer het hoogste stadium in de laatste 7 dagen . Gebruik de schaal van M1—d.w.z., stadia 0 - 4)*		
		a. Decubitus ulcus—wond veroorzaakt door druk resulterend in schade van het onderliggende weefsel		
		b. Ulcus van de venen—open wond die veroorzaakt wordt door een slechte bloedcirculatie met name in de onderbenen		
3.	**ZWEREN DIE ZIJN GENEZEN**	Patiënt had een zweer die **in de LAATSTE 90 DAGEN** is verdwenen/genezen 0. Nee 1. Ja		
4.	**ANDERE HUID-PROBLEMEN OF KAPOTTE HUID**	*(Kruis alle problemen van de laatste 7 dagen aan)*		
		Schrammen, builen		a.
		Brandwonden (tweede- of derdegraads)		b.
		Open wonden, geen zweren, uitslag, snijwonden (bv., kankerwonden)		c.
		Huiduitslag --intertrigo, eczeem, medicijn-, hitte-uitslag, herpes zoster		d.
		Huid ongevoelig voor pijn of druk		e.
		Huidsneetjes (anders dan door operaties)		f.
		Operatiewonden		g.
		GEEN VAN BOVENSTAANDE		h.
5.	**HUID-BEHANDE-LINGEN**	*(Kruis alle **behandelingen van de laatste 7 dagen aan**)*		
		Drukontlastingsmiddel(en) voor in de stoel		a.
		Drukontlastingsmiddel(en) voor in bed		b.
		Wisselliggingsprogramma		c.
		Voedings- of vochttoedieningsinterventie voor huidproblemen		d.
		Ulcusverzorging		e.
		Operatiewondverzorging		f.
		Verband (met of zonder plaatselijk toegepaste medicijnen), niet voor de voeten		g.
		Zalf/medicijnen (niet voor de voeten)		h.
		Andere preventieve/beschermende huidzorg (niet voor de voeten)		i.
		GEEN VAN BOVENSTAANDE		j.
6.	**VOET-PROBLEMEN EN VOET-VERZOR-GING**	*(Kruis aan wat van toepassing is in de laatste 7 dagen)*		
		Patiënt heeft één of meer voetproblemen—bv., likdoorns, eelt, knobbels, hamertenen, overlapping, pijn, slechte structuur		a.
		Voetinfectie—bv., voetschimmel, etteruitscheiding		b.
		Open wonden aan de voet		c.
		Nagels/eelt gedurende de **laatste 90 dagen** bijgeknipt		d.
		Kreeg preventieve of beschermende voetzorg (bv., gebruikte speciale schoenen, inleggers, kussentjes, teenscheiders, steunkousen)		e.
		Verband (met of zonder plaatselijk toegepaste medicijnen)		f.
		GEEN VAN BOVENSTAANDE		g.

SECTIE N. ACTIVITEITEN VERRICHTINGENPATROON

1.	**TIJD DAT DE PATIENT WAKKER IS**	*(Kruis de betreffende tijdsperioden over de laatste 7 dagen aan)* Patiënt is bijna altijd wakker (d.w.z. slaapt niet langer dan een uur per dagdeel) in de:		
		Ochtend	a.	
		Namiddag	b.	
		Avond		c.
		GEEN VAN BOVENSTAANDE		d.
(Als de patiënt comateus is, ga dan naar Sectie O)				
2.	**TIJD GEMID. BETROKKEN BIJ ACTIVI-TEITEN**	**(Wakker, terwijl men niet wordt behandeld of ADL-zorg ontvangt)** 0. Meestentijds—2/3 of meer 2. Weinig tijd—minder dan 1/3 1. Enige tijd—1/3 - 2/3 3. Geen tijd		
3.	**VOORKEUR-SETTINGS VOOR ACTIVI-TEITEN**	*(Kuis alle voorkeursettings voor activiteiten aan)*		
		Eigen kamer	a.	
		Dag-/activiteitenkamer	b.	
		In vph/weg van afdeling	c.	
		Buiten de instelling		d.
		GEEN VAN BOVENSTAANDE		e.
4.	**ALGEMENE VOORKEUR VOOR ACTIVI-TEITEN (afgestemd op de huidige mogelijkheden van de patiënt)**	*(Kruis alle voorkeuren aan, ook als de activiteit op dit moment niet voor de patiënt beschikbaar is)*		
		Kaarten/spelletjes	a.	
		Handwerk/kunst	b.	
		Oefeningen/sport	c.	
		Muziek	d.	
		Lezen/schrijven	e.	
		Geestelijke/godsdien-stige activiteiten	f.	
		Uitstapjes/winkelen		g.
		Wandelen/in rolstoel naar buiten		h.
		TV-kijken		i.
		Tuinieren of verzorgen van planten		j.
		(Gezellig) praten		k.
		Helpen van anderen		l.
		GEEN VAN BOVENSTAANDE		m.

Patiënt _____ Identificatienummer _____

5.	**WIL GRAAG VERANDERING IN DAGELIJKSE ROUTINE**	*Codeer wat de patiënt ten aanzien van de dagelijkse routines graag wil* 0. Geen verandering 1. Geringe verandering 2. Belangrijke verandering **a.** Soort van activiteiten waar de patiënt momenteel aan meedoet **b.** Mate waarin de patiënt bij de activiteiten is betrokken

SECTIE O. MEDICIJNGEBRUIK

1.	**AANTAL MEDICIJNEN**	*(Noteer het aantal verschillende medicijnen dat in de laatste 7 dagen is gebruikt; noteer "0" als geen enkele is gebruikt)*
2.	**NIEUWE MEDICIJNEN**	*Patiënt gebruikt op dit moment medicijnen waarmee in de laatste 90 dagen is begonnen* 0. Nee 1. Ja
3.	**INJECTIES**	*(Noteer het aantal DAGEN waarop de patiënt gedurende de laatste 7 dagen injecties ontving; noteer "0" bij geen enkele)*
4.	**DAGEN WAAROP DE VOLGENDE MEDICIJNEN ZIJN ONTVANGEN**	*(Noteer het aantal DAGEN in de laatste 7 dagen ; vul "0" in bij geen. Voor medicijnen die langer werkzaam zijn dan een week: tel als "1")* **a.** Antipsychotica **b.** Anxiolytica **c.** Antidepressiva **d.** Hypnotica **e.** Diuretica

SECTIE P. SPECIALE BEHANDELINGEN EN PROCEDURES

1. SPECIALE BEHANDELINGEN, PROCEDURES EN PROGRAMMA'S

a. SPECIALE ZORG —*Kruis ontvangen behandelingen en programma's aan van de laatste 14 dagen* **[Let op—tel alleen behandelingen van na de opname]**

BEHANDELINGEN		Ventilator of beademapparaat	l.
Chemotherapie	a.	**PROGRAMMA'S**	
Dialyse	b.	Alcohol & drugs-behandelprogramma	
IV-medicijnen	c.		m.
Intake/output-meting	d.	Verblijf op psychogeriatrische afdeling	n.
Monitoring van acuut medisch probleem	e.	Hospice-zorg	o.
Stomazorg	f.	Verblijf op pediatrie afdeling	p.
Zuurstoftherapie	g.	Vakantie-opname	q.
Bestraling	h.	Training van vaardigheden nodig voor terugkeer naar huis (bv., medicijnen innemen, huiswerk, boodschappen doen, vervoer, ADL's)	r.
Uitzuigen	i.		
Tracheostomazorg	j.		
Transfusies	k.	***GEEN VAN BOVENSTAANDE***	s.

b. THERAPIEËN - *Leg het aantal dagen en min. vast dat op de laatste 7 kalenderdagen elk van de volgende therapieën meer dan 15 min./ dag is gegeven. (Vul "0" in indien niet of bij minder dan 15 min./dag)* **[Let op—tel alleen therapieën van na de opname]**

(A) = # dagen gegeven van **15 minuten of langer**
(B) = totaal # minuten gegeven in de **laatste 7 dagen**

	DAGEN (A)	MINUTEN (B)
a. Logopedie en audiologie		
b. Ergotherapie		
c. Fysiotherapie		
d. Ademhalingstherapie		
e. Psychotherapie (door bevoegd therapeut)		

2. INTERVENTIEPROGRAMMA'S VOOR STEMMING, GEDRAG, COGNITIEVERLIES

(**Kruis alle interventies of strategieën aan** , ongeacht waar, die in de **laatste 7 dagen** zijn ontvangen)

Speciaal programma voor de evaluatie van gedragssymptomen	a.
Evaluatie in de **laatste 90 dagen** door een bevoegd psychotherapeut	b.
Groepstherapie	c.
Patiëntgerichte weloverwogen veranderingen in de omgeving om stemming/gedrag te veranderen—bv., kast geven om in te rommelen	d.
Heroriëntatie-therapie—bv, bewegwijzeren	e.
GEEN VAN BOVENSTAANDE	f.

3. VERPLEEGKUNDIGE REVALIDATIE/ REACTIVERING

Leg het AANTAL DAGEN vast dat op de laaste 7 dagen elk van de volgende verpleegkundige revalidatie- of reactiveringstechnieken 15 min./dag of meer is gegeven. (Vul "0" in indien niet of bij minder dan 15 min./dag)

a. Bewegingsuitslag (passief)		**f.** Lopen	
b. Bewegingsuitslag (actief)		**g.** Kleden/zich wassen	
c. Hulp bij spalk of tuigje		**h.** Eten of slikken	
TRAINING EN VAARDIGHEIDSPRAKTIJK IN:		**i.** Stomp-/prothesezorg	
d. Bedbeweeglijkheid		**j.** Communicatie	
e. Transfer		**k.** Andere	

4.	**MIDDELEN EN MAATREGELEN VOOR LICHAAMSFIXATIE**	(***Gebruik** de volgende codes voor wat betreft de **laatste 7 dagen** :)* 0. Niet gebruikt 1. Minder vaak dan dagelijks gebruikt 2. Dagelijks gebruikt Bedhekken **a.** — Volledige hekken aan alle open kanten van het bed **b.** — Andere soorten bedhekken (bv., half-hek, aan één kant) **c.** Bovenlichaamfixatie **d.** Ledemaatfixatie **e.** Stoel waaruit de patiënt niet kan opstaan
5.	**VERBLIJF IN ZIEKENHUIS**	Leg het aantal keren vast dat de patiënt **in de laatste 90 dagen** (of sinds de laatste beoordeling daarna) tenminste 1 nacht in een ziekenhuis heeft doorgebracht. (*Vul "0" in bij geen opnames*)
6.	**BEZOEK AAN EHBO-KLINIEK**	Leg het aantal keren vast dat de patiënt **in de laatste 90 dagen** (of sinds de laatste beoordeling daarna) zonder overnachting de EHBO-kliniek heeft bezocht. (*Vul "0" in bij geen bezoeken*)
7.	**ARTS-VISITES**	Op hoeveel dagen in de **LAATSTE 14 DAGEN** (of sinds de opname als dit kortergeleden is) heeft een arts (of bevoegd assistent) de patiënt onderzocht? (*Vul "0" in bij geen*)
8.	**DOKTERS-VOORSCHRIFTEN**	Op hoeveel dagen in de **LAATSTE 14 DAGEN** (of sinds de opname als dit kortergeleden is) heeft een arts (of bevoegd assistent) de doktersvoorschriften voor de patiënt veranderd? *Tel verlengingen **van** bestaande recepten niet mee.* (*Vul "0" in bij geen*)
9.	**AFWIJKENDE LABORATORIUMWAARDEN**	Heeft de patiënt gedurende de **laatste 90 dagen** (of sinds de opname) een uitslag van afwijkende laboratoriumwaarden gehad? 0. Nee 1. Ja

SECTIE Q. ONTSLAGMOGELIJKHEID EN ALGEHELE TOESTAND

1.	**ONTSLAGMOGELIJKHEID**	**a.** Uit/geeft de patiënt de wens aan voor terugkeer naar huis? 0. Nee 1. Ja **b.** Heeft de patiënt de steun van iemand die positief staat tegenover ontslag? 0. Nee 1. Ja **c.** Prognose van kort-verblijf— ontslag **binnen 90 dagen** gepland (omvat niet het sterven voor die datum) 0. Nee 2. Binnen 31 - 90 dagen 1. Binnen 30 dagen 3. Onslag-status onzeker
2.	**ALGEHELE VERANDERING IN ZORGBEHOEFTEN**	De algehele zelfredzaamheid van de patiënt is ten opzichte van de toestand van **90 dagen geleden** (of sinds de beoordeling daarna) wezenlijk veranderd 0.Geen verandering 1. Verbeterd—minder ondersteuning, minder hoog zorgniveau nodig 2. Verslechterd—ontvangt meer ondersteuning

Appendix 2. The MDS scales

This Appendix contains, for each MDS scale, the universal code of the applied MDS-items and their Dutch description. The response categories of the items can be found in Appendix 1.

ADL-Hiërarchie (ALD-SPH)

MDS-code	Item
G1eA	Verplaatsen op de afdeling Hoe de cliënt zich van plaats tot plaats in zijn/haar kamer en de gang ernaast op dezelfde verdieping begeeft. Bij gebruik van rolstoel: hoe zelfstandig daarmee
G1hA	Eten Hoe de cliënt eet en drinkt (ongeacht vaardigheid). Dit omvat ook het nuttigen van voedsel op andere manieren (bv. Sondevoeding, totale parenterale voeding)
G1iA	Toilet gebruik Hoe de cliënt de toiletruimte (of toiletstoel, pot of urinaal) gebruikt; op/van het toilet komt, doorspoelt, luier wisselt, omgaat met stoma/katheter, kleren in orde brengt
G1jA	Persoonlijke hygiëne Hoe de cliënt de persoonlijke hygiëne handhaaft, inclusief haarkammen, tanden poetsen, scheren, make-up aanbrengen, gezicht, handen en bilnaad wassen/drogen (NIET baden en douchen)

Cognitieve Problemen Schaal (CPS)

MDS-code	Item
B1	Comateus Voortdurend vegetatieve toestand/niet waarneembaar bewustzijn
B2a	Korte termijn geheugen Schijnt/lijkt zich na 5 minuten nog te herinneren
B4	Cognitieve vaardigheden voor de dagelijkse besluitvorming Nam beslissingen over taken van het dagelijks leven
C4	Zichzelf duidelijk maken Maakt de inhoud van de boodschap duidelijk, hoe dan ook
G1h(a)	Eten Hoe de cliënt eet en drinkt (ongeacht vaardigheid). Dit omvat ook het nuttigen van voedsel op andere manieren (bv. Sondevoeding, totale parenterale voeding)

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Depressie Rating Schaal (DRS)

MDS-code	Item
E1a	Negatieve uitspraken Het doet er allemaal niet toe; was ik maar dood; wat voor zin heeft het; het spijt me zolang te hebben geleefd; laat me sterven!
E1d	Voortdurend boos zijn op zichzelf of op anderen Zich gemakkelijk ergeren, boos op verblijf in verpleeghuis; boos over de ontvangen zorg
E1f	Uitingen van angst die niet reëel lijken Bang om in de steek te worden gelaten, alleen te zijn, samen met anderen te zijn
E1h	Steeds maar klagen over gezondheid Alsmaar vragen om de dokter, obsessief bezorgd zijn over lichaamsfuncties
E1i	Steeds maar zorgelijk klagen (niet met gezondheid samenhangend) Zoekt aldoor aandacht/geruststelling over dagindeling, maaltijden, de was, kleren, de omgang met anderen
E1l	Droevige, pijnlijke, zorgelijke gelaatsuitdrukking Diepe rimpels
E1m	Huilen, gemakkelijk tranen

Herziene Index voor Sociale Betrokkenheid (RISE)

MDS-code	Item
F1a	Op gemak in omgang met anderen
F1b	Op gemak bij geplande of gestructureerde activiteiten
F1e	Zoekt betrokkenheid in instelling Maakt/ houdt vrienden; neemt deel aan groepsactiviteiten; nieuwe activiteiten; helpt bij activiteiten van godsdienstige aard
F1f	Neemt uitnodigingen aan voor de meeste groepsactiviteiten Zoekt contact met anderen Gaat positief in op contact zoeken door anderen

Uitdagend Gedrag Profiel (CBP)

	MDS-code	Item
Conflict gedrag	E1d	Voortdurend boos zijn op zichzelf of op anderen Zich gemakkelijk ergeren, boos op verblijf in verpleeghuis; boos over de ontvangen zorg
	E4ba	verbaal lastigvallen Bedreigde anderen, schreeuwde naar ze, vloekte naar ze
	E4ca	lichamelijk lastigvallen Sloeg anderen, duwde, krabde, viel seksueel lastig
	E4ea	verzet tegen zorg Weigerde medicijnen/injecties, hulp bij ADL of bij eten
	F2a	bedekt/openlijk conflict met of herhaalde kritiek op zorgverleners
Terugtrek gedrag	E1o	terugtrekken uit activiteiten Geen interesse meer in wat men altijd deed of met familie/vrienden zijn
	E1p	minder omgang
Rusteloos en Repetitief gedrag	B5d	Perioden van onrust Frunikken of krabben aan de huid, aan kleding, servetten, enz.; vaak van lichaamshouding veranderen; herhaald bewegingen uitvoeren of schreeuwen
	E1n	motorische onrust IJsberen, handenwringen, rusteloos zijn, friemelen, plukken
	E4aa	zwerfgedrag Liep doelloos rond, zich schijnbaar niet bewust van behoeften of gevaar
Claimend gedrag	E1a	Negatieve uitspraken Het doet er allemaal niet toe; was ik maar dood; wat voor zin heeft het; het spijt me zolang te hebben geleefd; laat me sterven!
	E1b	aldoor vragen waar ga ik heen, wat doe ik dan
	E1c	aldoor uitroepen om hulp roepen (God sta me bij!)
	E1h	Steeds maar klagen over gezondheid Alsmaar vragen om de dokter, obsessief bezorgd zijn over lichaamsfuncties
	E1i	Steeds maar zorgelijk klagen (niet met gezondheid samenhangend) zoekt aldoor aandacht/geruststelling over dagindeling, maaltijden, de was, kleren, de omgang met anderen

Appendix 3. The SWON-scale, English & Dutch version

The scales for Social Well-being Of Nursing home residents

Assessment Information

The following questions concern social interactions of and with a resident in the past 3 months. These interactions involve the nursing staff, visitors, volunteers, other residents and any other staff. When the words 'nursing staff and others' are used, all of these people are included.
Choose the response-category that most applies to this resident.

Affection			scoring
How often does	1)	once a month or less	0
this resident show	2)	once a week	1
appreciation or	3)	several times a week	2
affection towards	4)	once a day	3
the nursing staff?	5)	several times a day or the entire day	4
How often does this	1)	once a month or less	0
resident get a hug	2)	once a week	1
(or a cuddle, etc)	3)	several times a week	2
from the nursing	4)	once a day	3
staff and others?	5)	several times a day or the entire day	4
How often is there	1)	once a month or less	0
humor in the	2)	once a week	1
contact with this	3)	several times a week	2
resident (nursing	4)	once a day	3
staff and others)?	5)	several times a day or the entire day	4
		subtotal	..... / 2 = ...

Behavioral confirmation		
Does this resident usually try to take others into account?	1) Yes	1
	2) No	0
Is this resident concerned about others?	1) Yes	1
	2) No	0
Does this resident usually try to keep to the agreements made?	1) Yes	1
	2) No	0
subtotal		..... * 2 = ...

Status		
Does this resident have a positive presence on the ward (f.i., humor, always happy, a special talent)?	1) Yes 2) No	1 0
Is this resident popular with the other residents?	1) Yes, with most 2) Yes, with some 3) No	1 0.5 0
Is this resident popular with the nursing staff?	1) Yes, with most 2) Yes, with some 3) No	1 0.5 0
	subtotal	.....* 2 =
		..... +
SWON-scale		Total.....

Sociaal Welbevinden Observatie Schaal

Informatie bij het invullen van de Sociaal Welbevinden Observatie Schaal

De volgende vragen hebben betrekking op de sociale interacties van de bewoner in de afgelopen maanden. De personen waar de bewoner contact mee kan hebben zijn natuurlijk verzorgenden, maar ook bezoek, vrijwilligers, andere bewoners en medewerkers van andere disciplines, bijvoorbeeld activiteitenbegeleiding. Als er niet specifiek 'verzorging' staat, moet u denken aan al deze mensen. Kies de antwoordoptie die het best past, ook al klopt deze niet precies.

Affecte		scoring
Hoe vaak toont deze bewoner waardering of genegenheid voor de verzorging?	O 1 keer per maand of minder O 1 keer per week O meerdere keren per week O 1 keer per dag O meerdere keren per dag of de hele dag	0 1 2 3 4
Hoe vaak krijgt deze bewoner een arm om zich heen of een aai over de wang (of een knuffel enz.) van verzorging en anderen?	O 1 keer per maand of minder O 1 keer per week O meerdere keren per week O 1 keer per dag O meerdere keren per dag of de hele dag	0 1 2 3 4

Hoe vaak is er humor in het contact met deze bewoner (verzorging en anderen)?	O 1 keer per maand of minder	0
	O 1 keer per week	1
	O meerdere keren per week	2
	O 1 keer per dag	3
	O meerdere keren per dag of de hele dag	4
	subtotaal	..... / 2 = ...
Gedragsbevestiging		
Probeert deze bewoner over het algemeen rekening te houden met anderen?	O JA	1
	O NEE	0
Bekommert deze bewoner zich om anderen?	O JA	1
	O NEE	0
Probeert deze bewoner zich over het algemeen aan de gemaakte afspraken en gebruiken van de afdeling te houden?	O JA	1
	O NEE	0
	subtotaal	..... * 2 = ...
Status		
Valt deze bewoner op een positieve manier op op de afdeling (bijvoorbeeld humor, altijd opgewekt, een speciaal talent)?	O JA	1
	O NEE	0
Is deze bewoner populair bij andere bewoners?	O JA, bij de meesten	1
	O JA, bij sommigen	0.5
	O NEE	0
Is deze bewoner populair bij verzorging?	O JA, bij de meesten	1
	O JA, bij sommigen	0.5
	O NEE	0
	subtotaal	..... * 2 = ...
		..... +
Sociaal Welbevinden Observatie Schaal		Totaal .....

Appendix 4. Reliability and Validity

In this Appendix, the types of reliability and validity that are studied in this thesis are discussed and explained briefly. This description is largely based on the book by Steiner and Norman (1995), and for a further elaboration, the reader is directed thereto.

The scales described in this thesis measure so-called constructs. A construct is a theoretical concept, a small theory, about a combination of behaviors or attitudes. Depression, for instance, is not readily observable like height or weight, but causes symptoms and behaviors that *can* be measured, such as tearfulness and utterances of uselessness, worry or hopelessness. The mini-theory on depression describes a particular combination of these symptoms and behaviors that can be attributed to depression. What is measured by a scale for the construct 'depression', thus depends on the researcher's theory of depression. Other examples of constructs are pain, dementia, anxiety, motivation and intelligence.

Reliability is the extent to which a scale is measuring something reproducible, thus yielding similar results in varying circumstances. This means that the scores on a reliable scale do not depend much on who is doing the assessment (i.e., nurse A or nurse B), where the assessment is taking place (i.e., nursing home C or nursing home D), or when (i.e., today or tomorrow). In this thesis, three forms of reliability are studied. Firstly, *the intra-rater reliability,* also called the test-retest reliability. This is the agreement between multiple assessments of one scale made by one rater. Secondly, *the inter-rater reliability,* which is the agreement between multiple assessments of one scale made by two raters. Thirdly, *the internal consistency.* This is the extent to which the items of a scale relate and together measure one underlying dimension. For instance, it indicates whether the formulated items about diminished interest in activities, uselessness, worry and hopelessness together measure one thing, from which may follow that this scale will measure the construct of depression.

Validity is the extent to which the scale is measuring what it is supposed to measure. The vantage point for validity is *construct validity.* Construct validation is a process of hypothesis testing. Consequently, throughout the thesis, hypotheses are formulated to study the scales' validity. Construct validity refers to various methods that are used to determine whether a scale is able to tap a particular construct, of which convergent and discriminant validity are the most important. *Convergent validity* is tested when the aim is to improve an existing scale by better representing the construct it is measuring. It can be tested by correlating the new scale to the existing scale. More importantly, one should test the correlation of both scales with a third scale, to which the construct is related theoretically. For instance, suppose that depression is related to anxiety, then

both depression scales should be related to the scale for anxiety, but the new depression scale should correlate more satisfactory with the scale for anxiety, as it is supposed to be a better representation of the construct. *Discriminant validity* is the extent to which the scale does indeed not correlate with constructs with which it should not correlate. For instance, suppose that depression is independent from intelligence, the scales for depression and intelligence should not correlate. Strictly speaking, concurrent validity is not part of construct validity. When testing *concurrent validity,* the aim is for the new scale to perform as good as the comparison measure of known validity, which can be tested by correlating the new scale to the existing scale. This procedure can, as described, also be used for convergent validity, but the two types of validity testing differ with regard to the goal of developing a new scale: convergent validity refers to improving the existing scale, whereas concurrent validity refers to replacing the existing scale, for instance because the new scale is more easy to administer or less costly. The last type of validity used in this thesis is *content validity.* Content validity is about the extent to which the dimensions of a construct are represented in a measure, and is typically an important aspect of scale construction. When a scale for depression incorporates not only depressive mood, but, for instance, also diminished interest in activities, worry, insomnia and feelings of worthlessness, it represents the construct better. This will lead to more accurate conclusions on the persons that are studied.

Samenvatting

Dit proefschrift gaat over de kwaliteit van leven van verpleeghuisbewoners, en in het bijzonder over het meten ervan. Uit interesse in de hoogte van iemands kwaliteit van leven volgt de vraag of en hoe diens kwaliteit van leven verbeterd kan worden, en (later) of een bepaalde interventie succesvol is geweest. Deze informatie kan alleen worden verkregen als bekend is hoe kwaliteit van leven moet worden gemeten en als daarvoor een goed meetinstrument beschikbaar is. Dat is echter niet makkelijk, want hoewel kwaliteit van leven een populair begrip is, staat nog steeds ter discussie uit welke (levens)domeinen het precies bestaat. Voor verpleeghuisbewoners is een complicerende factor dat veel van hen niet over hun kwaliteit van leven kunnen communiceren, bijv. door afasie of andere cognitieve beperkingen. Daarom was het doel van dit proefschrift om een conceptuele benadering voor kwaliteit van leven te vinden die geschikt is voor verpleeghuisbewoners, en daarnaast om een goed middel te vinden om die kwaliteit te meten. Er is hiertoe antwoord gezocht op de vraag of kwaliteit van leven kan worden gemeten door middel van het observeren van gedrag van bewoners, in plaats van hen naar een eigen oordeel te vragen. Op deze manier worden alle verpleeghuisbewoners erbij betrokken, ook diegenen die niet meer goed kunnen communiceren.

Meer specifiek is onderzocht of voor dit meten de Minimum Data Set (MDS) van het Resident Assessment Instrument (RAI) kan worden gebruikt. De MDS is een standaardmethode voor het in kaart brengen van de medische, functionele, psychosociale en cognitieve toestand van een bewoner en bestaat uit 100 observatievragen. Het RAI, waarvan de MDS een onderdeel is, is een geautomatiseerd cliëntenvolgsysteem dat het zorgproces en het

proces van zorgplandefiniëring ondersteunt. Elk kwartaal geeft het, via de MDS, een totaalindruk van de toestand van de bewoner, en signaleert vervolgens de mogelijke aanwezigheid van bepaalde gezondheidsproblemen. Door middel van gestandaardiseerde analyseprotocollen kunnen de gesignaleerde problemen op een gefundeerde en gestructureerde manier worden onderzocht. Op basis van MDS-vragen zijn in de afgelopen jaren verschillende meetschalen geconstrueerd die het mogelijk maken om in één oogopslag het beloop van het cognitief functioneren, de zelfstandigheid bij de uitvoering van Activiteiten van het Dagelijks Leven, de stemming en de sociale betrokkenheid te volgen (zie de Bijlage).

Omdat de MDS wereldwijd wordt gebruikt, lag het voor de hand om de bruikbaarheid van juist die methode te bekijken. De precieze kwaliteit van de schalen in de Nederlandse verpleeghuissituatie is echter nog niet bekend. Een mogelijk probleem is bovendien dat de MDS relatief weinig vragen bevat over psychosociaal welbevinden, en zich met name richt op problemen in plaats van op sterke punten van bewoners. Daarom is in dit proefschrift onderzoek gedaan naar zowel de kwaliteit van de vragen in de MDS als naar de mate waarin de MDS alle voor kwaliteit van leven belangrijke domeinen meet.

Hoofdstuk 2 gaat over de vraag of er conceptuele modellen voor kwaliteit van leven bestaan die zich richten op de gehele verpleeghuispopulatie en die gebruikt kunnen worden bij het verbeteren (of behouden) van de kwaliteit van leven van verpleeghuisbewoners. Er zijn drie criteria geformuleerd waaraan een model moet voldoen om bruikbaar te zijn. In de eerste plaats moet het model in de basis voor iedereen gelden en het hele begrip 'kwaliteit van leven' omvatten (en niet domeinen die bijvoorbeeld alleen met gezondheid te maken hebben). Ten tweede moet het model uitleggen hoe de verschillende domeinen in grote lijnen met elkaar samenhangen, zodat er een inschatting kan worden gemaakt van de gevolgen en te ondernemen acties wanneer er op één van de domeinen iets mis gaat. Ten derde moet ze ruimte bieden aan individuele verschillen. Een model dat aan die drie criteria voldoet kan verzorgenden, andere professionals en familie handvatten geven voor een adequate bijdrage aan de kwaliteit van leven van de bewoners.

Uit literatuuronderzoek kwamen zes modellen naar voren, waarvan er maar één voldeed aan alle drie de criteria: de theorie van de Sociale Productie Functies (de SPF theorie). De basisaanname van deze theorie is dat voor iedereen het allerbelangrijkst is dat hij/zij zich goed voelt, dus subjectief welbevinden ervaart. Welbevinden wordt bereikt door persoonlijke bronnen te gebruiken. Bronnen zijn dingen die iemand doet en heeft zoals sporten, werken, vrienden, toegang tot gezondheidszorg en geld. Tot op zekere hoogte zijn deze bronnen inwisselbaar, dus na verlies van de één (bijv.

een partner) kunnen andere (bijv. vrienden) (meer) worden 'gebruikt' om toch welbevinden te ervaren. Het wordt moeilijker wanneer zoveel bronnen verloren gaan dat compensatie door het gebruiken van andere bronnen steeds moeilijker wordt. Dit is veelal het geval bij verpleeghuisbewoners. Zij worden steeds afhankelijker van anderen om hen te helpen bij het bereiken van welbevinden. Van degenen die hen helpen is dan vereist dat zij heel goed weten hoe ze moeten bijdragen aan de kwaliteit van leven van de bewoners.

De SPF theorie is gebruikt om te bepalen welke aspecten van kwaliteit van leven gemeten moeten worden.

Het bepalen van de bruikbaarheid van de MDS startte met het door middel van statistische analysetechnieken onderzoeken van de betrouwbaarheid en validiteit van de bestaande MDS-meetschalen. Betrouwbaarheid betreft de mate waarin de uitkomsten op een schaal beïnvloed zijn door toevallige omstandigheden, bijvoorbeeld de persoon die de schaal invult, of het tijdstip waarop. Validiteit gaat over de vraag of echt wordt gemeten wat men denkt te meten. Zo mag een schaal voor 'depressie' niet ook 'angst' meten. Verzorgenden van negen verpleeghuizen vulden de MDS-vragenlijsten in voor in totaal 227 bewoners. Van deze bewoners is extra informatie verzameld door middel van interviews. Met al deze gegevens zijn de betrouwbaarheid en validiteit van de MDS-schalen in de dagelijkse praktijk onderzocht.

Hoofdstuk 3 beschrijft de evaluatie van de drie MDS-schalen voor Activiteiten van het Dagelijks Leven (de ADL-SPH), cognitie (de CPS) en depressie (de DRS). De ADL-schaal bleek zeer betrouwbaar en valide te zijn. De cognitieschaal had een goede validiteit, en de betrouwbaarheid was goed voor bewoners van somatische afdelingen (afdelingen voor bewoners met hoofdzakelijk lichamelijke aandoeningen), maar wat minder (ruim voldoende) voor bewoners van psychogeriatrische afdelingen (afdelingen voor dementerende bewoners). De betrouwbaarheid en validiteit van de depressieschaal waren matig, zeker op psychogeriatrische afdelingen. Dat de depressieschaal minder goede kwaliteiten heeft dan de ADL- en de cognitieschaal is niet verrassend; het is bekend dat het moeilijker is om psychische en sociale aspecten van gedrag te meten. De conclusie van hoofdstuk 2 is dat de ADL-schaal en de cognitieschaal van de MDS bruikbaar zijn, en dat de depressieschaal toegepast zou kunnen worden bij bewoners met ten hoogste matig-ernstige cognitieve stoornissen. Voordat de depressieschaal bij ernstige dementie toegepast kan worden, dient echter verder onderzoek te worden uitgevoerd.

Hoofdstuk 4 doet verslag van het onderzoek naar de betrouwbaarheid en validiteit van de MDS-schaal voor Sociale Betrokkenheid (ISE). Omdat

er twijfels waren over de juistheid van de definitie van het begrip 'sociale betrokkenheid' zoals dat door de ISE wordt gemeten, zijn andere schalen over positief sociaal gedrag opgezocht. Vervolgens is aan 20 artsen en psychologen uit de verpleeghuispraktijk gevraagd of ze de verschillende aspecten van het begrip wilden beoordelen op hun relevantie voor de verpleeghuisbewoner. Zij bleken twee aspecten die niet in de ISE aanwezig waren heel belangrijk te vinden: 'zoekt contact met anderen' en 'gaat in op contact zoeken door anderen'. Bovendien bleek dat twee vragen die wel in de ISE zaten door de experts als niet (zo) van belang werden beoordeeld. Nadat ook de statistische analyses op Canadese en Nederlandse bewonergegevens hetzelfde resultaat gaven, zijn de twee oorspronkelijke ISE vragen verwijderd en twee nieuwe toegevoegd. Deze nieuwe schaal, de RISE (zie de Bijlage), bleek een betere betrouwbaarheid en validiteit te hebben dan de ISE, vooral bij bewoners met aanzienlijke cognitieve stoornissen. Er wordt aanbevolen om de twee nieuwe vragen in de internationale MDS op te nemen.

De volgende stap bij het bepalen van de bruikbaarheid van de MDS was een poging om met MDS-vragen een nieuwe meetschaal over psychosociale aspecten te maken. **Hoofdstuk 5** beschrijft de constructie van een schaal voor uitdagend gedrag (ook wel probleemgedrag genoemd). Vijf klinische experts hebben uit de MDS vragen geselecteerd die volgens hen gaan over gedrag van de bewoner dat irritatie, frustratie en/of afwijzing kan veroorzaken bij professionals, andere bewoners en bezoekers. Volgens de bovengenoemde SPF theorie ondermijnt dit gedrag de bereidheid (bewust of onbewust) om de behoeften van de bewoner te vervullen. Het welbevinden van de bewoner komt hierdoor in gevaar. Statistische analyses op gegevens van 656 bewoners resulteerden in een betrouwbare en valide schaal van 15 MDS-vragen, het Uitdagend Gedrag Profiel (CBP; zie de Bijlage). Deze schaal bestaat uit 4 subschaaltjes: conflict gedrag, teruggetrokken gedrag, claimend gedrag en rusteloos en repetitief gedrag. Bij analyses van gegevens van 227 andere verpleeghuisbewoners kwamen iets minder goede, maar toch nog voldoende, kwaliteiten naar voren. De conclusie is dat de CBP een belangrijke aanvulling op de MDS-schalen zou kunnen zijn.

Hoofdstuk 6 beschrijft de ontwikkeling van een positieve observatieschaal voor sociaal welbevinden. Deze schaal is gebaseerd op vragen over onderwerpen die volgens de SPF theorie belangrijk zijn voor kwaliteit van leven, maar niet in de MDS aanwezig zijn. In samenspraak met mensen uit de praktijk werden vragen geformuleerd, die vervolgens werden getest in een groep van 308 verpleeghuisbewoners. Hieruit kwam een schaal van negen vragen naar voren, bestaand uit drie subschaaltjes voor de

drie dimensies van sociaal welbevinden (affectie, gedragsbevestiging en status). Aanvullende analyses van gegevens van 165 andere bewoners lieten zien dat de schaal een voldoende tot goede betrouwbaarheid en validiteit heeft. Deze nieuwe schaal, de SWON (zie de Bijlage), kan een waardevolle aanvulling zijn om de kwaliteit van leven van verpleeghuisbewoners te meten. Ze meet namelijk aspecten van sociaal welbevinden die belangrijk worden gevonden in het dagelijks leven in het verpleeghuis, maar die tot nu toe nog geen expliciete aandacht kregen in meetschalen.

Hoofdstuk 7 gaat over de bruikbaarheid van schalen voor algemene kwaliteit van leven (subjectief welbevinden) die het eigen oordeel van bewoners meten, de zogenaamde zelfbeoordelingschalen. Het eigen oordeel is een moeilijk punt in het verpleeghuis, omdat veel bewoners door cognitieve stoornissen minder goed in staat zijn tot een gesprek, en wellicht zelfs ook een oordeel, over kwaliteit van leven. De scores van de bewoners op zes verschillende schalen zijn vergeleken. De vragen van de Depressielijst bleken voor bewoners met ernstige cognitieve stoornissen het meest eenvoudig te beantwoorden. Samen met een andere schaal, de Geriatrische Depressie Schaal, had de Depressielijst ook de beste betrouwbaarheid en validiteit. Desalniettemin bleek dat deze zelfbeoordelingschalen andere resultaten gaven dan observatieschalen voor welbevinden, vooral bij bewoners met ernstige cognitieve stoornissen. Het is echter niet duidelijk welke resultaten het meest te vertrouwen zijn, de eigen uitspraken van de bewoners of de observaties van de verzorging. Daarom is verder onderzoek hiernaar noodzakelijk.

De conclusie van dit proefschrift is dat de MDS tot op zekere hoogte kan worden gebruikt bij het meten van kwaliteit van leven. Het meten van kwaliteit van leven door middel van een observatieschaal, zoals de MDS, is een noodzakelijk uitgangspunt, omdat de validiteit van zelfbeoordeling nog ter discussie staat. Ook in dit proefschrift bleek dat de samenhang tussen het eigen oordeel enerzijds en observatie door anderen anderzijds, laag is. De MDS blijkt vooral op het niveau van de bronnen voor welbevinden te gebruiken. Er zijn MDS-schalen voor Activiteiten van het Dagelijks Leven, cognitie, uitdagend gedrag als 'anti-bron' en een aantal individuele vragen over andere bronnen. Op het niveau van het welbevinden zelf heeft de MDS minder mogelijkheden. De depressie schaal (die een inschatting geeft van het subjectieve welbevinden) bleek minder goed bruikbaar bij bewoners met ernstige cognitieve stoornissen. De RISE meet sociale betrokkenheid en is te beschouwen als een goede voorspeller voor sociaal welbevinden. Om de drie componenten van sociaal welbevinden volgens de SPF-theorie te meten was het evenwel nodig een extra schaal te maken (SWON). In dit

proefschrift is niet expliciet gekeken naar fysiek welbevinden, naast sociaal welbevinden de tweede hoofdcomponent van welbevinden. Ook voor deze component is te verwachten dat de MDS op bronniveau wel, maar op het niveau van welbevinden minder, kan bijdragen aan het meten van kwaliteit van leven. Het betrouwbaar en valide meten van kwaliteit van leven door aan de bewoners zelf te vragen hoe het met ze gaat blijft een belangrijk doel van nader onderzoek. Hetzelfde geldt voor het verbeteren van de depressieschaal en het betrouwbaar en valide meten van fysiek welbevinden.

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Vele anderen hebben een meer concrete bijdrage aan dit proefschrift geleverd, waarvoor ik hen graag wil bedanken. In de eerste plaats geldt dit voor de verzorgenden, artsen en vooral de bewoners die deel hebben genomen aan het onderzoek. Hoewel het onderzoek geen direct belang voor henzelf of de dagelijkse praktijk leek te hebben, staken zij er veel energie in. Met name wil ik noemen mijn contactpersonen Anneke en Marian, Conny en Dennis, Fred, Henk, John, Joost, Lisette, Peter en Theo, Ria, en Wilco, die vaak erg hun best hebben moeten doen.

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En tot slot weer naar het begin. Lieve mam en Karen. Omdat we samen wel meer stormpjes hebben doorstaan en ik heel blij ben dat ik jullie heb, is dit boek voor jullie.

Curriculum Vitae

Debby Gerritsen werd geboren op 6 oktober 1973 in Winterswijk. Van 1985 tot 1991 doorliep zij het VWO aan de R.K.S.G. Marianum te Groenlo. In 1997 behaalde zij haar doctoraaldiploma Psychologie aan de Katholieke Universiteit Nijmegen, met als afstudeerrichting Psychogerontologie. Na werkervaring te hebben opgedaan als onderzoeksassistent en projectmedewerker aan de vakgroep Psychogerontologie, begon zij in juni 1998 aan haar promotieonderzoek bij het EMGO-Instituut. Sinds januari 2003 is zij werkzaam bij de Stichting Verenigde Amstelhuizen in Amsterdam. Zij is projectmedewerker van het 'RAI-project', een project dat zich richt op de implementatie van het Resident Assessment Instrument in de verpleeg- en verzorgingshuizen die zijn aangesloten bij de Verenigde Amstelhuizen.

List of other Publications

Achterberg, W., Holtkamp, C., Pot, A. M., Frijters, D., Gerritsen, D., & Ribbe, M. (in press). *Probleeminventarisatie in de verpleeghuiszorg: Effecten van implementatie van het Resident Assessment Instrument (RAI)*. In P. Groenewegen & T. van den Bosch (Eds.), Zorg, opvang en begeleiding van chronisch zieken.

Frijters, D., Gerritsen, D., & Steverink, N. (2003). *Zorginhoudelijke kwaliteit, betrouwbaarheid en bruikbaarheid van observatiegegevens in de benchmark voor verpleeg- en verzorgingshuizen.* [Care quality: reliability and usefulness of observation data in bench marking nursing homes and homes for the aged in the Netherlands]. Tijdschrift voor Gerontologie en Geriatrie, 34, 21-29.

Gerritsen, D., Kuin, Y., & Steverink, N. (2004). *Personal Experience of Aging in the Children of a Parent with Dementia*. The International Journal of Aging and Human Development, 58, 147-165.

Gerritsen, D. L., Jongenelis, K., Steverink, N., Ooms, M. E., & Ribbe, M. W. (in press). *Down & Drowsy? Do apathetic nursing home residents experience low quality of life?* Aging and Mental Health.

Gerritsen, D. L., van der Steen, J. T., & Jonker, C. (Eds.). (2001). *Het beoordelen van de kwaliteit van leven bij demente ouderen*. Leo Cahn Stichting, Symposiumverslag 2000. Amsterdam: Lundbeck B. V.

Jonker, C., Gerritsen, D. L , Bosboom, P. R., & Van Der Steen, J. T. (2004). *A Model for Quality of Life Measures in Patients with Dementia: Lawton's Next Step*. Dementia and Geriatric Cognitive Disorders, 21, 159-164.

Jonker, C., Gerritsen, D.L., van der Steen, J.T., Bosboom, P.R., van Campen, C., Kleemans, A. H., & Schrijver, T.L. (2001). *Kwaliteit van leven en dementie I. Model om welbevinden bij demente patiënten te meten.* [Quality of life and dementia. I. Model for the assessment of wellbeing in dementia patients] Tijdschrift voor Gerontologie en Geriatrie, 32, 252-258.

Jongenelis, K., Gerritsen, D. L., Pot, A. M., Ooms, M. E., Eisses, A. M. H., Beekman, A. T. F., Kluiter, H., & Ribbe, M. W. (subm.). *Screening for depression in the nursing home setting: A short and user-friendly version of the Geriatric Depression Scale*.

Jongenelis, K., Pot, A. M., Gerritsen, D. L., Eisses, A. M. H., Beekman, A. J., Derksen, M., Kluiter, H., & Ribbe, M. W. (subm.). *Diagnostic*

Accuracy of the Original 30-item and Shortened Versions of the Geriatric Depression Scale in Nursing Home Patients.

Van der Steen, J. T., van Campen, C., Bosboom, P.R., Gerritsen, D.L., Kleemans, A.H., Schrijver, T.L., & Jonker, C. (2001). *Kwaliteit van leven en dementie II. Selectie van een meetinstrument voor welbevinden op 'modelmaat'*. [Quality of life and dementia. II. Selection of a measurement instrument for wellbeing appropriate for the reference model] Tijdschrift voor Gerontologie en Geriatrie, 32, 259-264.